EXPERIENCES OF SILENCE IN END-OF-LIFE CARE:

A phenomenological study

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Abstract

When we honestly ask ourselves which person in our lives means the most to us, we often find it is those, who instead of giving advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a warm and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in our hour of grief and bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is the friend who silently cares.

-Henri Nouwen

This research was undertaken in order to seek a way of acknowledging and understanding the lived experience of people giving and receiving palliative care. Utilising the World Health Organisation's philosophy of palliative care which underpins the New Zealand philosophy of palliative care, the research explored what was important for the person and family receiving care, and what was of importance to the health professionals providing care at the end-of-life.

Using a phenomenological methodology informed by van Manen and Heidegger, this research incorporated unstructured audio taped interviews with people receiving care, their family members, the bereaved, and members of the interprofessional teams delivering care. The process of being open to the direction participants wanted to journey through this research invited a co-constructed method of engagement. The outcome of the research reveals the lived experience of silence in end-of-life care, incorporating the themes:

Silent moments
Silence as suffering and compassion
Silence as connection
Intuitive silence and gratitude
Being silent for others
Silent meaning of symbolic language

Each narrative offered by participants was a paradigmatic case in its own right, with strong patterns of meaning. The narratives hold rich descriptive information necessary for understanding the role of silence. Silence is a complex phenomenon, with implications on how to 'be with' another in the final acts of living. It is a powerful and helpful form of communication and compassionate, supportive companionship. It is person-centred and can convey meaning when there are no easy answers. For health care professionals to be effective with the art and science of silence we must be comfortable in silence ourselves. Our caring intention begins with the self and ripples out to colleagues and supports compassionate communities of care.

This research reconnected with the history of caring for the dying in our community and with some of the ancient wisdoms about silence, offering insights from the past that may support the path to our future.

This research will be of interest to health professionals involved in palliative care, and the research community, highlighting a need to tell our stories and use them to learn and reflect upon the essence of human-to-human connectedness through the role of silence. By doing so we give voice to the less articulated yet important experiences in our practice.

Acknowledgements

Sincere gratitude goes to the participants who so generously gave of their time for this research, sharing their stories and experience of palliative care. The interprofessional health care teams delivering services, the families receiving care, and for those willing to talk to me during a time of loss and grief following the death of a much-loved family member. Your individual gift of time is received with respect and gratitude so that we may learn to support and improve end of life care in our community. I have endeavoured to interpret your stories with humility and dedication that your openness and honesty deserves.

To the Professorial team who supported this journey with your patience, experience, mentorship and wisdom as my supervisors, my heartfelt thanks. Anne Richardson, Andrew Hornblow and Sandy Macleod began this journey with me and were latterly joined by Alison Dixon who, as a nursing colleague and friend, complimented the team, supporting a nursing lens to this work, giving clear direction and encouragement to ‘trust the process’. To Margaret Patterson, our health librarian, you are amazing, thank you! To my transcriber Gill, your skill was very valuable to the completion of this work, thank you also.

It is customary to thank family and friends who support a PhD journey. I am in the privileged position of knowing I have unconditional love and support from all my family (especially my husband Matthew and son Richard) and close friends in all I do in life, and that sustains me when life’s challenges are presented as they invariably do when one embarks on a long journey of study. However, in keeping with the theme of this work, it appears I have been silent in acknowledging this work has been undertaken. I hope when you find out, the surprise will be a pleasant one. I do wish to acknowledge two of my family who have walked this path before me and have been an inspiration in quite different disciplines of academic achievements, Emeritus Professor Glynnis Cropp (French) and Dr Jeremy Robertson (Engineering).

Thank you all for making this possible.

Table of Contents

List of Figures

Key to Transcriptions

The following information is the key to the abbreviations used within the research findings.

[ ]	Information added to clarify context or meaning
(…)	Words, phrases or sentences edited out
…	Pause present within the narrative
Italics	Participants' quoted narrative

Lucinda handwriting 10 point font is used for a poem

Editorial Style

I have chosen to involve myself in the writing of this thesis by using the term ‘I’. I will use the term ‘we’ and ‘us’ to include the readers and myself. This is aimed at facilitating a notion of shared experiences and emphasises the intersubjective nature of the research. I am not suggesting that we can generalise from the nature of this research but we can accept that in one person’s story there will be aspects that will resonate with others.

Writing Style

This thesis is largely written as hermeneutical text. My wish is for the reader to “see” something meaningful in the phenomenon of silence. To dwell reflectively, to be touched by this lived experience of compassionate caring.

Referencing Style

APA 6th edition referencing style has been used, except where books have been referred to in extracts from the reflective journals. These books have not been referenced as they are mentioned in the personal context of journal writing.

Names

To ensure confidentially and protection of identity, all names used in this thesis for the research participants are pseudonyms.

Chapter 1 Researcher Interest

Introduction

A story has no beginning or end: arbitrarily one chooses that moment of experience from which to look back or from which to look ahead. -Graham Greene

My nursing career began in oncology where I was to learn that cancer affected not only the person experiencing it but also their friends and families. It was a time when treatment options and survival rates were not as successful as they are today and this experience affected the whole person in every sense. I had an inspiring oncology ward sister who supported my practice and taught me significant values by which I practise today. I discovered that I had a skill for connecting with and supporting people in their illness experience. I enjoyed the science behind the treatment options and relief of troubling symptoms. I also discovered the art of my practice by understanding the need that people had for harmony with their surroundings, to help them make sense of a senseless time in their life. For the patients who died and their families, I aimed to provide the best possible support and care that I could, but there was a gap in my practice knowledge, one that I couldn't identify fully or understand. This, I was later to discover, was the Hospice philosophy of care, which I was introduced to at the Royal Marsden Hospital, London. The Hospice movement had not developed in New Zealand at this time.

During my overseas palliative care work and study experiences I came into contact with people who had a wide variety of different cultural and spiritual values and this challenged me to look at my own. I also had to examine ways I communicated, as a lot of my overseas experience was spent with non-English speaking patients. During this time of evolution in my career I came to realise that palliative care was an area of nursing from which I would obtain the most satisfaction. I had found my niche in hospice palliative care nursing.

I have been involved with the world of palliative care nursing for many years now and held positions ranging from the bedside practice, to management, leadership, consultancy, governance, education and research. I teach from my experience of many years at the bedside, and intuition from personal and professional journeys of being in the moment with the dying experience. I have some notion of the commonality, uniqueness, and differences, along with many unanswered questions regarding the complexity of practice when I enter into the world of the dying and the I-thou dialogue. I have had the privilege of working, engaging with and learning from the early pioneers of the palliative care movement in New Zealand and overseas, and reflect back from early beginnings in the field of caring for the dying with excitement, challenges, pride in the progress made, humility and wonder at the human story of having and losing, loving and grieving.

I view my praxis in palliative care nursing through a caring science lens which is congruent with the philosophy of palliative care. Caring science is an ethical-spiritual-existential philosophy that seeks to combine science with the humanities and arts and is the work of Jean Watson. It provides a framework for me to study, research, explore, identify, describe, express, and question the relation and intersection between and among the ethical, ontological, epistemological, methodological, pedagogical, and praxis aspects of my nursing (Watson, 2008). Palliative care calls for a qualitatively deeper way of being in relationship with others, be they the person in our care, their family or our health care colleagues/team. There are elements of Caritas Literacy or 'ontological competencies' or people skills that are common to palliative care practitioners (Watson, 2008, p.24). They include but are not limited to, consciousness, intentionality, centering, authentic presence, deep listening, accurately detecting feelings of others present, and hearing behind the words. Being able to form deep trusting relationships within a short time frame is useful when we may only meet people in the final hours to a few days of their lives and are invited into their life world to provide a healing presence at this most intimate and personal time. A time of uncertainty, intense suffering and death. Palliative care calls for us to be self-aware, self-reflective and come to terms with dying and death, I am not as effective in my practice if I have not lived an examined life. Watson's theory of human caring and the caritas processes invite me to explore and utilise all ways of knowing, doing, being and becoming to meet the needs of those in my care.

Palliative care has come of age, is an identified speciality in its own right, the service is available in most developed countries and it has a strong presence within New

Zealand health care. Hospices are the pre-eminent palliative care providers in the community and are now defined as specialist palliative care services. The vision for palliative care service provision in the New Zealand Palliative Care Strategy (Ministry of Health [MOH], 2001) states that “all people who are dying and their family/whanau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way” (p. 70). This vision for New Zealand is based on the World Health Organization (WHO) (2016) definition of palliative care being: “an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (p. 1). This definition is expanded by offering nine key practice points suggesting palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The philosophy of palliative care therefore is all encompassing, available to people across the lifespan and offers guidance to practitioners on the fundamental principles of effective care. Whilst this should be supportive to both the givers and receivers of care, palliative care colleagues throughout the country highlight increasing concerns. They come together to share their collective practice care journeys during their course of postgraduate study that I currently have the pleasure of supporting them with. They raise more questions than they answer but there is a clear emerging theme of stress with rising demands on services, aging workforce, limited resources and challenges with management. Stories are shared of power, bureaucracy, pain, courage, hope, despair, loneliness, and a diminishing respect for each other in conjunction with increasing demands on services. These stories offer the opportunity to reflect how we go forward as a service and a society to care for our dying. What is the strategic direction we should be taking in New Zealand and are we being challenged by our own success in offering specialist services to the dying, that we are missing the fundamental point for end of life care? As hospice and palliative care services are challenged to meet growing demands with limited resources, do we need to challenge our basic philosophical underpinnings? Do we fully understand what people who are dying and their family/friends need from us?

Having witnessed exemplary practice and the successful management of distressing physical symptoms thanks to modern medicines and delivery systems, and seen the benefits of working in multidisciplinary teams in an interprofessional way, I have still seen the limitations of our scientific, technological and caring abilities and witnessed suffering and unresolved (and perhaps unresolvable) issues especially pertaining to social, psychological and existential angst. In asking how this can be in today's modern age with so much at our finger tips I was taken on a journey of discovery, delving back into ancient Geek times and the beginning of Western medicine and the teachings of the great physician Hippocrates and the God of healing – Asklepios (Kearney, 2000). Hippocratic medicine concentrated on healing the curable conditions, emphasising the need for rationalised evidence-based practice using external agents to achieve his goal whereas Asklepian healing concentrated on helping those suffering from incurable conditions. Asklepios believed healing came from within, that each individual had a spontaneous tendency towards wholeness when they paid attention to their whole and inner selves, a psychological and spiritual healing practice. Here was a culture and time that respected two very different but complementary models of care. It was an integrated health care system which attended to people as whole persons – mind, body, soul and spirit. These intertwined approaches co-existed in a relationship of mutual respect and harmony in Greece but over time they have become split and separated from each other. The teaching of Hippocrates is still clearly seen in medical models but what has happened to Asklepios? His emblem is still alive – the serpent coiled around a staff, is still seen in some journals, some pharmacies, and some ambulances, so maybe not totally forgotten but maybe lost in translation as to its meaning. Covertly Asklepios can be in the patients' subjective experiences of inner healing and transformation and in the compassionate caring of those who attend to them, those who are willing to be fully in the moment of another's suffering.

Michael Kearney in his book *A Place of Healing* (2000) offers the following snapshot of the defining aspects of both systems to allow us to see the potential for healing if we could integrate both models in our clinical approach to care: pp. 36- 38.

Hippocratic Medicine	Asklepian Healing
Draws on objective evidence. • Tangible, objective, reproducible data • Depends on carer using outer senses, sight, sound, touch, taste, smell	Draws on subjective evidence • Includes external awareness but primarily refers to within • Depends on carer using emotion, instinct, intuition and somatic awareness
Calls for clinical objectivity • Carer remains objective and separate • Does not get over involved and therefore lose professional judgment to effectively treat	Calls for clinical subjectivity • Impossible to help people in their suffering without entering in their experience with them • Dictum 'physician know thy self' applies
Treats pain and lessens suffering by intervening from without	Healing of suffering from within
Works as an 'opus contra naturam' • Pain is only a problem to be solved	Healing works with nature • Suffering is both a problem to be solved and a question to be lived
Primary training involves knowledge and skills	Primary training involves self-knowledge

Asklepian temples contained harmless serpents. It was thought their mystical hypnotic gaze was healing and the fact they shed their skin was also symbolic of new beginnings. This translates well into palliative care. The gaze corresponds to our attention to the patient - placing them in the centre of our care, being, listening, waiting and respecting. The healing comes from the careful application of our knowledge while attending to them. Currently in palliative care we see Hippocratic traditions taking the lead – we talk about evidence-based care, we follow our work place/organisational protocols, guidelines, patient pathways, and measurable outcomes. The *Hospice New Zealand Standards for Palliative Care* (2019) is an example of a framework to guide and support services to provide consistent high-quality care irrespective of where the person and family may be.

Asklepian traditions are there with discussion around quality of life, dignity, holistic care and spirituality but they have become distorted as they have been interpreted in terms of the Hippocratic lens – with protocols, training courses, measurements, audits and scales. Do we need to consciously and deliberately invite Asklepain philosophy back into our health care institutions to relight the metaphorical lamp of health and wellness and a place of healing? Would this notion of care assist in the confusion related to changes in our society with web-based medicine and consumer rights? Patients' choice is now being seen as their right to have the treatment they want irrespective of futility, harm and the confusion it causes – strong words maybe, but this easier approach has replaced the art in our practice of having the challenging conversations around the difficult dance of living and dying (Reid, 2012).

I am a strong supporter of reflective practice, through which I have continued to deepen my understanding towards contemplative practice and resulting conscious-intentional caring-healing practice, continuously challenging myself to find new and creative ways of enabling meaningful caring-healing relationships to occur with those I am caring for, with the team I am working with and the colleagues I support thorough their educational journey into palliative care. I begin to question, is there another way? As I consider searching for answers I am introduced to Patricia (pseudonym), and a challenging and stimulating conversation unfolds in the following extract from my journal, capturing her story.

> Patricia phones me and we agree to meet. I am doing a favour for a friend of a friend, Patricia wishes to know if she has pathological bereavement issues following the death of her partner. This professional couple came together mid-life and enjoy a fast and social relationship, snatching moments of time somewhere in the middle of their hectic working lives. She describes him as a "wine snob" who enjoys fine dining in his favourite restaurant that he has religiously dined at every Friday night since it opened. After experiencing this ritual, Patricia feels this relationship has great potential and it is a lifestyle she would enjoy becoming accustomed to. The same time each Friday, the same table

and same banter with the sommelier on tonight's choice. A life limiting cancer diagnosis with referral to palliative care on diagnosis is a shocking reminder of the fragility of life. Friday night an empty table is followed by a call from the restaurant in the morning, "is everything alright?" They will come back as soon as they can but, in the meantime, he is too unwell. A member of the palliative care team visits and explains the wrap around services and how they are there to support them both . . . they have not seen them since, they slip through the system. I am suddenly aware that I lose concentration on her story as I feel cross, disappointed and wonder how this could have happened? What is wrong with the system? I work to bring myself back into the moment with her, how did you manage, who supported you I ask? "The restaurant of course" she replies. I catch myself grinning, she notices, and I am invited to explain that we never stop learning, and that in 40 years of my involvement in this area of nursing, I have not heard of a restaurant playing a major role in palliative care and I need to learn more. The story continues, Friday night a knock at the door, one of the chefs from the restaurant armed with food has come to cook the meal, they had discussed the importance of routines and rituals in the restaurant and they wished for that to continue for this couple, and until he was well enough to return to the restaurant, they would be coming to cook for them each Friday. A few weeks later she phones, "thank you for your kindness, he is no longer able to eat, he is taking sips of fluid only and too weak now to get out of bed, it won't be long, I will phone you when it is all over". Friday night comes and the familiar knock on the door and the chef comments that she can still eat, it is important to keep her strength up and the meal will be simple and quick to eat but gives her a break from the bedside to be cared for, for a short time. Besides, he explains, "you said he was able to sip fluids, look!" a bottle of red from the top shelf, and only a Riedel glass to sip it from of course – he is the wine snob after all. Too weak to hold the glass himself, they position his frail body adequately for him to enjoy a sip, that final smile will live on in her memory as he dies peacefully in the early hours of the next morning. (Reflective moments in practice, abridged, reflexive journal).

Patricia informs me that whilst not normally a red wine drinker, she finishes the bottle that night and is worried such behaviour might lead to a drinking problem and asks if this is normal? A supportive conversion between us unfolds as she finds comfort in our meeting and I thank her for the gift of her story, enabling me to think about how, in being let down by the professional services, the community has an opportunity to play its part. Reaching out with an act of compassion and expression of human caring, maintaining ritual and routines, offering a touch of kindness, the spirit of holistic care is illuminated. How do we then connect our professional services back into the community and vice versa? Would this be a helpful way forward to meet demands and empower/nurture/educate society in the care of the dying?

I turn to research to explore, describe and conceptualise the lived experience of my colleagues - health professionals involved in palliative care delivery - and explore and describe experiences, thoughts and ideas of the person and/or family who are receiving palliative care services, to uncover the meaning that people give to these experiences, which may identify unmet needs or opportunities for the provision of palliative care in the future.

Aim

To explore, describe and conceptualise the wishes and needs of the person who is dying and their family and explore the lived experience of the health professionals involved in palliative care by:

1. Describing, identifying and portraying the personal experiences of those who give and receive care at the end of life
2. Seeking to determine whether the experiences and perceptions of delivering palliative care according to the World Health Organisation and Ministry of Health philosophy of care within the community
3. Exploring opportunities to fulfil any unmet community need for end of life care
4. Awakening a shift of consciousness that creates new realities and creative opportunities to unfold for the provision of palliative care in the future

5. Expanding current understanding of reciprocity in relationships between health professionals delivering palliative care and patients receiving it.

At the time of considering this research, a personal conversation with the CEO of Hospice New Zealand revealed they were also wanting to know what it is that people in our community need from palliative care and therefore what needs to be in place to meet these expectations. This research can contribute to that understanding.

Structure of Thesis

In this initial Chapter 1, I have introduced myself as the researcher, and described my background and the philosophical underpinnings that helped to shape and support my experience in palliative care. I have introduced the palliative care philosophy, adding a brief mention of Hippocratic and Asklepian philosophy as background information. A catalyst story is shared, leading into the research aims.

In Chapter 2, I revisit the historical beginnings of caring for the dying, and the beginning of the modern era of hospice and palliative care and how this shaped the New Zealand context. The guiding principles and strategic documents are acknowledged and future demographic predictions are offered for consideration, raising awareness of potential demands on services for the future.

In Chapter 3, I discuss the philosophical underpinning and theoretical framework of phenomenology that underpins the design of this research and has guided me through the method for conducting the research.

In Chapter 4, I outline the research method. The design as originally intended, including the application for ethical approval, followed by the reality of how the methodological process unfolded.

Chapter 5 presents the analysis and shares with the reader, the themes that unfolded and supporting literature. Stories from the participants and reflective entries from my researcher journals which highlight the themes, invite time to reflect, identify and connect with the gift of these experiences.

Chapter 6, offers the opportunity to take note of the unintended consequences of the research. This chapter reveals how, if we are open to the possibilities that a research project offers, it invites consideration of additional aspects that can be explored further in subsequent research.

In Chapter 7, I discuss and synthesise the findings from (Chapters 5 and 6). Through honouring the lived experience of the participants and inviting consideration of Silence as a caring component of human-to-human caring in end of life care. The phenomenological approach to this inquiry does not provide definite answers but aims to stimulate reflection and conversation about the experience of silence in end-of-life care.

In Chapter 8, I present my concluding comments. Here I offer some reflections on the research journey, the research design and methodology. I also note the implications of the findings, and need for future research.

Chapter 2 Is the Past Our Future?

You have to know the past to understand the present. –Carl Sagan

In the previous chapter I situated myself within the context of this research, introducing myself as the researcher, and explaining my interest in, and rationale for this research. This chapter will consider the historical beginnings of caring for the dying in society and the beginning of modern hospice and palliative care services. The early British history has influenced the New Zealand context, and this chapter will capture our early beginnings, the guiding principles and strategic documents, and offer future demographic predictions for consideration, raising awareness of potential demands on services for the future.

Early beginnings

Today hospice care, end-of-life-care and palliative care are known terms in medicine and society. Hospice, palliative care units and community services have developed over past decades in Western societies and people can die supported by professionally trained health professionals. Palliative medicine has become a specialist field in its own right, with national and international associations for those specialising in the field. It is however, still considered a fairly young phenomenon as formal recognition of this field of medicine didn't occur until 1987, when the United Kingdom was acknowledged as the first country in the world where palliative medicine gained this status (Clark, 2016).

The 1960s-1970s is the time period credited with the early beginnings, when Cecily Saunders founded St Christopher's hospice in London in 1967 and shortly after, the first palliative care unit was established in the acute hospital setting in Montreal under the direction of Balfour Mount (Billings, 1998). Balfour Mount visited St Christopher's hospice in 1974 after being inspired by the writings of Cecily Saunders and Elizabeth Kübler-Ross but he struggled with the term 'hospice' as the French translation was synonymous with homes for the poor and moribund. He investigated the early etymology of the Latin term *pallium*, to cloak and to hide or cover' which in modern terms is considered to mean 'to improve the quality of'. Cecily Saunders liked the term and began using it and referring to the Montreal palliative care service which was the start of the focus of care being moved outside of a hospice service to encompass other settings (Clark 2016).

In acknowledging Cecily Saunders as the founder of the modern hospice movement, it is worth remembering the earlier foundations to end-of-life care. In 1887 William Munk, a London based physician, had published his work on an 'easeful death' calling for skilful sympathetic care of the dying patient. This was followed by prominent physicians and surgeons such as Herbert Snow (1898), William Osler (Bliss, 1999), and Alfred Worcester (Kerr, 1992) who all wrote wisely on the topic, but their influence at the time was limited, and the care of the dying remained neglected. Stolberg (2017) discovered in his exploration of early manuscripts on the history of palliative care, that the term *palliative* was used centuries before the aforementioned authors. The oldest vernacular use of the term *palliative* appeared in 1543, in a printed work by Giovanni da Vigo, when, writing about cancer, da Vigo contrasted 'eradicative cure' with a 'palliative cure'. Also associated with de Vigo's writing is the first known definition: "a cure palliative is, when a disease is cloked for a reason, not perfytlye healed" (p. 21). Stolberg (2017) also found the earliest monograph, by Kuchler in 1692, which outlines three types of treatment, suggesting that, if the treatments are understood correctly, they make the complaint easier to bear for the patient and also for the people around them. Illness that had a life limiting outcome such as scurvy, epilepsy, melancholia and leprosy, would have been offered palliative treatment (p. 25). The notion of 'palliation' was also shaped by the Latin meaning *palliare* – laying a cloak over something or covering something up. This was linked to cancer when ulcerated breast lesions, persistent ulcers or anal fistulas at that time were considered inoperable by surgeons such as da Gigo and de Chauliac, and the area would be covered over to assist with exudate and smell. In modern times this early etymology is often referred to, to include elements of caring, to cloak/wrap the patient in protective medical treatment and empathetic caring. The *person* becomes cloaked rather than the illness or defect.

From the late sixteenth century onwards, the concept of alleviating or 'palliative' treatments was firmly established for people with incurable illnesses or who were dying. The essential task was to relieve pain. Liquid laudanum was most commonly used but also nightshades, northern water hemlock and mandrake root. The term ‘opiate’ referred to a mixture of different remedies, depending on the doctors experience of using them. Unrelenting cancer pain was most feared at this time but it was observed that opiates were also helpful in addressing sleeplessness, cough, diarrhoea and difficulty breathing. In many cases, palliative treatments were considered superior to the dangers or complications from surgery (Stolberg, 2017).

The early modern period was also profoundly influenced by religious belief. Where the dying could be granted eternal salvation, or the soul be cleansed through purgatory or be condemned to eternal damnation, was decided at the time of death. Therefore, pastoral presence at the bedside was imperative. The French historian Phillippe Aries offered ground-breaking work about the *Ars Moriendi* (translates from Latin as the ‘art of dying’) suggesting a positive picture of death in the early modern period, with people dying at home with family, friends and community supporting them, being able to say their farewells and finding comfort in rituals that accompanied the dying and death, which were visible in everyday life. Death was an integral part of daily life in villages and towns as it was only a very small minority who died in hospitals or alms-houses. Finding hope in a better life after death supported both the dying and their families. This peaceful image of death where one entered into the dying time willingly, in harmony with God and those they were leaving behind and in the hope of a better life after death as Aries depicted, has been challenged by his many critics, who question whether it does justice to the subjective perceptions and experience of the dying and their families. Despite his critics, Aries’ seminal work is still viewed as profound and insightful (Sloane, 1991).

Medical care had a more discrete presence at this time because of the significance of faith and the religious art of dying. If the Doctor was called, his role was to inform that death was imminent and calling the clergy was advisable. Porter and Porter (1988) suggest the beginning of medicalised dying, referring to alleviation of physical suffering with medicines, occurred in the second half of the eighteenth century. They suggested that there was a gradual shift in emphasis, where the doctor and clergy worked together to give comfort to the dying. Trevelyan (1946) notes the shift of the Scottish influence into England, moving surgery from the “trade of the barber surgeon into the science of the specialist” (p.345). This improvement in professional skill was supported by the foundation of hospitals, with 154 hospitals established over 125 years from 1700 (Treveleyan, 1946).

The modern time of the nineteenth to early twentieth century brought far reaching changes in Western society. People were living longer and dying of chronic (tuberculosis) and incurable (cancer) diseases rather than acute illnesses. There was also a cultural change where religious belief was losing significance and physical pain was no longer seen as a divine test best managed by the clergy, but rather a meaningless experience that required medicines to manage it. Worldly ideas were beginning to overtake religious norms. Barker-Benfield (1992) noted that compassion for others was a sign of a cultivated and sophisticated character and along with physical pain being difficult to bear for those suffering from it, it was also difficult for those witnessing it. The concept of the humane, concerned and committed doctor found its way into the medical literature. It was acknowledged that caring for the dying was not easy but if carried out successfully, it becomes a source of joy for the physician (Baltes as cited in Sloane, 1991)[1].

Subsequently, there was significant progress in understanding the human body with microscopic examination, chemical analysis, x-rays and bacteriology encouraging therapeutic optimism and medical action rather than palliative treatment which was becoming viewed as unrewarding. Medical students were no longer required to take an interest in the care of the dying and there was no specific training offered. William Munk in 1887 (as cited in Sloane, 1991) noted there was very little in the medical literature on the management of the dying, or therapies that might be helpful to alleviate suffering, and he noted young physicians starting out, had to teach themselves what to do or not do, when caring for the dying. Munk also wrote about the role of nursing at this time, which he supported to provide a calm, natural undisturbed death. He opposed the common practice of darkening the room and forcing fluids when one was

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[1] Baltes, Wilhelm. (1842). De euthanasia. Berlin: Nietack. Baltes original work is not available in English, therefore secondary cited in Sloane (1991).

not able to swallow and believed fresh cool air was helpful to those suffering lung complaints. He was strongly influenced by Florence Nightingale's writings (*Nightingale's Notes on Nursing*, 1959) and in addition, championed the importance of nourishing food, favouring milk, cream, beaten eggs, and cereal, over beef tea, and also asserted that wine and spirits are of special use in the treatment of the dying, aiding circulation and digestion and suggesting champagne as the best choice, but noting it needs to be given more frequently than other wines or spirits. In all cases, the wishes of the patient are the most reliable guide to what should be given. Munk, describes the goal of the physician in helping the sufferer to a more comfortable death in his 1887 book entitled *Euthanasia*. He is clear that care should be taken to avoid even the accidental premature death of the dying patient by the incautious administration of opium. It was not until the beginning of the twentieth century that the modern sense of euthanasia, understood as a deliberate medical intervention to end life, was fully articulated. According to Jalland (1996), *Euthanasia* remained the authoritative text on medical care of the dying for the next thirty years. Nurses were encouraged to see that supporting someone to die easily and peacefully was one of the greatest privileges of nursing. Paying attention to any distress such as restlessness may indicate a full bladder for which a catheter would give relief, dry mouth could benefit from ice chips, lemonade, or tea with lemon could be soothing. Munk recommended alcohol as a stimulant if required, and nurses were to be guided by the wishes and ability of the patients as they would observe when nature was to take its course. If the person was no longer able to swallow safely, no further nourishment would be offered. Tasks performed were those that aided comfort, all temperature taking and physical examinations were ceased.

We know very little about these earlier times from the perspective of the dying person and the care they received. To be cloaked with the comfort of caring physicians and nurses, offered nutrition and fluid and champagne in the final days and being free of any unnecessary interventions sounds almost ideal. Until well into the twentieth century the majority of people died at home surrounded by family but their circumstances varied depending on their social situation. What has been noted Stolberg (2017), is that the accounts at this time are reflective of the experiences of the nobility and middle classes. But many people in the age of industrialisation, urbanisation and pauperism spent their last days in misery, in beds or on bags of straw shared with others, with no money for medication and many died on the streets. In spite of efforts to improve the care of people with cancer, consumption and dropsy (the most common illnesses at the time), many experienced unrelieved pain and tormenting symptoms. It was also a time of restraint for psychological reasons not to disclose that death was imminent as it may make the person feel more miserable. It was only viewed important to offer the truth in a ‘gentle manner’ about dying if it was deemed helpful for people to put their affairs in order and to attend to the salvation of their soul (Stolberg, 2017, p.144).

Significant change came between 1800 and 1970, with inpatient institutions influencing how end-of-life care was managed, and these continue to shape our current services today. Hospitals in medieval and early modern times were largely a place of care for the poor who had no one willing or able to care for them, a refuge for the blind, deaf, insane, disabled, epileptics and the chronically ill. Although a doctor or surgeon often visited the larger hospitals, they were not set up as medical institutions. People often lived there for years until they died, but caring for the dying was not the main purpose (Phipps, 1988). Hospices in centuries past were primarily hostels or inns for travellers or pilgrims on a journey and were situated at mountain passes or bridges. As Clark (1999) states, “the idea that hospices, as places concerned specifically for the dying have a history stretching back into the early times is misleading, and serves little purpose in advancing the understanding of such care in the past” (p. 66).

Social and economic change from the industrialisation and urbanisation of the late eighteenth century influenced the change in role for hospitals to care for the curably ill workers and return them to the workforce. The workforce at the time were young, and less likely to have experienced major illness or chronic conditions, and therefore physicians gained confidence in treating simple acute illness, and developed new knowledge and skills. This meant that people wanted to enter hospitals for treatment, because they were no longer seen as places that housed the poor and destitute and admissions soared. Inevitably some people did die despite the best medical treatments offered and society found it increasingly acceptable to die in hospital following attempts to treat. Dying shifted from home surrounded by family, to dying in hospitals (Clark, 1999).

With increasing success in treating the curably ill, demand for beds rose and those living with chronic and incurable illness were frequently not admitted, or were discharged rapidly to free up beds. Clark (1999) also notes that at the end of the nineteenth century the main reason for rejecting or discharging the incurably ill was hospital reputation. Mortality rates became the standard measure for quality of care. Reputational risk, hospitalisation being of no benefit to the patient, and caring for the dying causing a rise in expenditure, all meant that it was simply best not to have the dying in hospital. As noted earlier, in the late eighteenth and early nineteenth century, it was considered that caring for the dying was an important duty of medical care yet the hospital, the best possible place for that care was becoming inaccessible to those who needed it. With time, the plight of the incurably sick and their need for care was noticed and cities throughout Europe opened dedicated hospitals to care for people with incurable disease. Italy opened *ospedali degli incurabili* hospitals, France founded *hospices des incurables,* Ireland and England *royal hospital for incurables* and the USA followed shortly after Clark (1999). They were not solely focused on the care of the dying, more care of the chronically ill but they do deserve a mention in the prehistory of the modern hospice movement.

The more direct precursors to the modern hospice movement were London-based and supported by the churches and the Sisters of Charity. They included the Hostel of God (established in 1892), St Columba (1889), St Luke’s Hospital (1893) and St Joseph’s House (1905). Admissions were predominantly people with cancer and tuberculosis with an anticipated life expectancy of four months or less. People were discharged if they did not die within the predicted time frame. Good nursing care, use of opioids and a more joyful atmosphere, contrasting with the serious, mournful way of caring for the dying in other institutions was noted by both patients and medical professionals (Goldin, 1981).

Profound changes in caring for the dying occurred post World War II, with significant improvement in medical innovation, new drug developments for hypertension and diabetes, antibiotics assisting tuberculosis, general improvement in nutrition and quality of life, improvement in surgical techniques and intensive care units able to keep people alive, combined to offer significant possibilities. Cancer, cardiovascular disease and stroke were the main cause of death in industrialised countries until AIDS took hold in the 1980s. Hospitals provided a new hope for cure and therefore many more lives ended in hospital once more, although now, dying was more impersonal because, in the process of trying for cure, and people ended up with interventions, ventilators and tubes. Dying was marginalised and became a taboo subject and hospitals were identified as having grave deficiencies especially regarding mental and emotional support (Field, 1994). Shepard (1976) commented that physicians had been taught to cure, so "when they realise that cure is no longer possible, their own insecurities concerning death prevent them from comforting their patients and supporting them in ways that are not clinical" (p. 97).

In the 1960s, Elizabeth Kübler-Ross was instrumental in encouraging talking about death and dying in the public arena in America. Her book *On Death and Dying*, published in 1969, became a best seller, with its case studies in the form of conversations with people who were dying. She was opposed to death repression in society. "The more we are making advancements in science, the more we seem to fear and deny the reality of death" (p. 6). "He may cry for rest, peace and dignity, but he will get infusions, transfusions, a heart machine or a tracheostomy if necessary" (p. 8). She wrote well, and drew the public's attention to the needs of the dying but has been criticised for perceived self-promotion and reluctance to recognise her colleagues who were also working hard to change the medical system at the time. Parkes (2013) respectfully critiques Kübler-Ross' book some 40 years after writing the foreword to her original work, balancing the facts and situating her work with other medical colleagues of the time.

The 1960s saw social and cultural changes, starting in the United States and the United Kingdom, and spreading to Europe and other parts of the globe. The 1960s were an era of protest. The civil rights movement protested against the unfair treatment of those from minority racial groups**.** Towards the end of the decade more and more Americans protested against the Vietnam War and more rights for women were demanded. The birth control pill and other contraceptives were introduced. Hierarchies and traditional authority were challenged. Society was protesting against everything that was mainstream**.** The medical world did not escape the tide of discontent, with the patriarchal 'Gods in white coats' notion (Illich, 1977). The patients' rights movement gained momentum, and people sought alternative and complementary medicine as alternatives to mainstream treatments, and sought emotional and spiritual support, that was deemed missing in mainstream health care. At the same time Elizabeth Kübler-Ross was publicly raising the plight of the dying, bringing the topic into the public arena. Cecily Saunders had actively begun to address the needs of the dying. In 1959, she appealed to health care professionals by planning for a hospice that would address the medical, emotional, spiritual and nursing needs of the dying. St Christopher's Hospice was opened in 1967. She had collected a wealth of experience that would support this initiative from her experience of war time nursing and as a social worker at St Thomas hospital in 1947 where she supported many dying people in unrelieved pain from cancer. She learnt about pain management through volunteering at St Luke's Hospice and was considering returning to nursing when she was encouraged by Norman Barrett, a surgeon, who said "go and read medicine. It's the doctors who desert the dying and there's so much to be learned about pain. If you don't do it properly you'll only be frustrated, and they won't listen to you" (Saunders, 2001, p.430). She decided to undertake medical training. She then worked at St Joseph's Hospice, building on her observations of people in pain and administering analgesics on a regular basis to manage pain rather than waiting for patients to ask for it once the dose had worn off. This formed the basis to how we practice today. In 1967, the year St Christopher's Hospice opened, she published her handbook *The Management of Terminal Illness*. This gave guidance on pain management, encouraged open honest conversation with patients about their illness and dying, emphasis on emotional and spiritual needs of the terminally ill and advocacy for close personal attention and affection. Like her predecessors, she also supported the therapeutic use of alcohol to assist in pain management.

St Christopher's Hospice was not a new idea but it was through the work of Cecily Saunders, her writings, research and public addresses on the needs of the dying, that she demonstrated success that saw St Christopher's become the model for many institutions throughout the world including New Zealand (Hayley & Sachs, 2005).

Despite St Christopher's success, there was concern that hospices might become ghettos for the dying, that the public would perceive them as a place of death, and therefore promote the marginalisation of dying (Stolberg, 2017). The second concern was whether hospices would have the necessary diagnostic and therapeutic competence and technology that might be needed to provide adequate pain management. This gave rise to establishing palliative care units/wards within hospitals to enable care of the terminally ill to benefit from health care personnel and the technology as required and embed medical palliative care into the heart of health care. The Palliative Care Unit of the Royal Victoria Hospital in Montreal, established in 1975 under the direction of Balfour Mount, was the first palliative care unit in the world to operate in this way. Mount had spent time with Cecily Saunders, and had undertaken his own pilot study of implementing Saunders' suggestion amongst cancer patients at the Royal Victoria Hospital, and found that the care of the dying and support for families were much improved with this new initiative (Saunders & Kastenbaum, 1997). Mount supported open dialogue on the reality of a person's condition and supported an interdisciplinary approach to care for the holistic needs of people. He also modelled another way of being with people, encouraging doctors to sit on the bed of a patient and connect with them as a person, at times putting their professional role to one side. The idea of the palliative care unit being integrated into a general hospital was soon emulated around the world (Lewis, 2007).

This snapshot of history allows us to look back on caring for the dying as a very old tradition, where people provided the best care available with the crude beginnings of medicine to cure the body and input from the clergy to cure the soul. The goals of care were then as they are now, to alleviate suffering in its holistic sense, providing support for the dying and their families. In the late nineteenth/early twentieth century, interest in end-of-life took a back step with the growing optimism of progression in medicine, improved technologies, drug treatments and surgical techniques, as more could be done to support life rather than death. This lasted about 100 years during which time a lot of wisdom and knowledge faded, until Elizabeth Kübler-Ross, Cecily Saunders and Balfour Mount – the early pioneers of the modern hospice movement, championed a way forward.

New Zealand context

New Zealand followed a very similar history of palliative care. Suzanne Aubert (better known as Sister Mary Joseph and Mother Aubert), the French born nun who founded the Home of Compassion hospital for 'incurables' in Wellington in 1907 (caring for orphans, handicapped children and terminally-ill women), could rightfully be called the founding pioneer of New Zealand's palliative care service. She was also a pioneer of district nursing and caring for Māori in Hawke's Bay and in the Wanganui river areas as early as 1871. She lived for many years in Hiruharama (Jerusalem), on the upper banks of the Wanganui River, establishing a Catholic Mission there. Her gift was to combine good medicine, common sense, laughter, friendship and love in a holistic view of life and health where intense spirituality was all around (Munro, 1996). Her medical and nursing skills were unquestioned. Having studied medicine at the French Faculty of Lyons she was debarred from obtaining a degree because of her gender. Shortly afterwards she travelled to New Zealand and immersed herself in Maori culture and language. She learnt about and dispensed Maori herbal remedies, which were the chief proprietary medicines of that time, and wrote the first collection of New Zealand natural remedies. Within fifty years she also opened a soup kitchen for the unemployed, the first day nursery and children's home in Wellington, and a foundling home in Auckland, and composed a wealth of spiritual writings collected as *The Directory* (Munro, 1996). Her teachings to her nursing nuns were centred on practising with love and learning to live fully.

> Every bit of caring for people is to be done with love where the loving itself is also to be a perpetual exercise in learning to live fully. Love is the life of the heart, and like the pendulum of the clock which sets in motion all the other parts, love gives to the soul all the movement it has… Suzanne Aubert, 1910, (as cited in Munro, 1996, p201).

Suzanne Aubert's writings also provide us with her insights in watching, learning and fostering non-sectarian tolerance and co-operation (Dunmore, 1990). Rather than just responding to the needs of the terminally ill by caring for them, Aubert moved also into large scale planning for their ongoing care and protection. She canvassed business, local government, national politics, medicine and law in order to establish and maintain her Home of Compassion and to train her nuns to be nurses –'the best nurses in Wellington'… it permeated the whole of the hospital, this warmth and this compassion' (Gibbs, as cited in Munro 1996).

The Little Company of Mary (LCM, which had been founded in England by the venerable Mary Potter) developed Calvary Hospital in Wellington in 1929 and the Sisters of Mercy opened Mater Misericordiae in Auckland in 1952, showing the strength of religious women underpinning the care of dying in early New Zealand history. In the 1960s a bequest enabled the LCM to build a centre for cancer patients at Calvary Hospital. In the mid-1970s the ground floor of Calvary Hospital was a 24-bed geriatric assessment ward, whose charge nurse was Sister Margaret Lancaster, LCM, working with a general practitioner, Dr Michael Shepherd, who had previously worked at Saint Christopher's Hospice, London. A shortage of beds at Wellington Hospital, saw referrals to the Mary Potter Ward to be cared for there. Sister Margaret and Dr Shepherd had a vision that this ward should develop as a hospice and accordingly approached the LCM in order to see if they could provide some facilities for terminal care. In 1987 the Sisters sold Calvary Hospital which enabled them to establish the Mary Potter Hospice Foundation. This effectively gifted the hospice to the people of Wellington (McCabe, 2004).

On the strength of the success of the modern hospice movement in the United Kingdom and Canada, New Zealand's palliative care services developed from the 1970s with home-based care and the establishment of inpatient services from 1979 onwards, with Mary Potter Hospice, opening in Wellington in June 1979. Later that year, Te Omanga Hospice in Lower Hutt, and Saint Joseph's Mercy Hospice in Auckland, were also opened. These initiatives grew with community philanthropic support rather than any national health policy planning and today there are 32 hospice services in New Zealand and 14 hospital palliative care services, including one specialist paediatric service (MOH, 2012, HNZ n.d.).

A grant from the Cancer Society of New Zealand supported the establishment of a national body, and Hospice New Zealand was established in 1986 (Hospice New Zealand, n.d.). Similar to the British and Canadian services, hospice services in New Zealand were intertwined with cancer care. Hospice New Zealand's first objective was to improve the quality of terminal and palliative care in New Zealand. Based in Wellington, it was also tasked with negotiating with Government and other national bodies for the good of the hospice movement in New Zealand, negotiating national policy affecting the future development of hospice programmes of care, and developing standards. Hospice New Zealand's objectives are to:

1. Extend the provision of palliative care services – a wider range of people in a wider range of places receive hospice services and support

2. Develop a transparent, equitable and sustainable funding model and apply it across the sector
3. Enhance value for members – take leadership nationally on a diverse range of issues
4. Create, extend and enhance community relationships – enabling powerful and collaborative relationships with community. (Hospice New Zealand, 2016)

The Department of Health (now Ministry of Health) commissioned a report in 1992 to establish foundational information to support the future direction of hospice services and related policy. This report highlighted the need to determine the relevant level and mix of services required in different communities and the need for coordination in a fragmented service environment. It supported the strong community input and noted the need for specialised skills (Barnett & Smith, 1992). Hospice was subsequently identified as an essential health service, with a recommendation that the Regional Health Authority fund this service. In 1997 the Ministry of Health, in partnership with the National Health Committee, Hospice New Zealand and the Health Funding Authority, commenced the 'Care of the Dying' project which provided clear specifications of services, settings, and service providers required to care for people receiving palliative care (MOH, 2001). The 2001 national strategy had the agreed priorities of:

1. Assessment and care coordination
2. Clinical Care
3. Support care.

These priorities supported the national work plan which encompassed a number of projects designed to facilitate more effective provision of care being delivered by the community based and inpatient facilities across New Zealand (MOH, 2012). Despite having been written in 2001, the Palliative Care Strategy has many aspects that remain relevant today, including that all people who are dying and their family/whānau who could benefit from palliative care, have timely access to quality palliative care services that are culturally appropriate and are provided in a coordinated way (p. vii).

New Zealand acknowledges the WHO (2015) principles of palliative care but developed these further (MOH, 2017a, b, c) to acknowledge the needs of Māori and New Zealand's guiding documents for health and consumer rights:

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection and the importance of He Korowai Oranga (Māori Health Strategy, 2002).
2. Palliative care recognises and respects the rights of patients as detailed in the New Zealand Code of Health and Disability Services Consumers' Rights (Code of Health and Disability Services Consumers' Rights Regulations 1996, 2014).
3. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whānau in contemporary New Zealand.

The New Zealand definition (MOH, 2017a) of palliative care acknowledges that "primary palliative care" should meet the palliative care needs of the majority of people with a life limiting illness. "Primary palliative care" is provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team (MOH, 2015). A primary palliative care provider has an ongoing role in the care of people with a life limiting illness in the community and includes general practice teams, Māori health providers, allied health teams, district nurses and residential care staff. Primary palliative care is provided in the hospital by general ward staff, as well as disease specific teams (MOH, 2015). Specialist providers, comprising hospice teams and hospital-based consult services, provide direct patient care for those with the most complex needs, whilst at the same time providing education and consultation with primary palliative care providers. Involvement of specialist teams is understood to be either episodic or continuous, depending on the patient's needs (MOH, 2015).

Collaboration between government agencies and Hospice New Zealand has been providing leadership to support the future direction. The Palliative Care Council was established in 2008 to provide independent advice to the Minister of Health and to report on New Zealand's performance in providing palliative and end-of-life care. In 2011 the council undertook a national health needs assessment for palliative care, identifying the services required to meet identified need and comparing current services. They used hospital discharge and mortality data to develop estimates of palliative care need on a population basis, this was a Phase 1 Report. The Phase 2 report was released in 2013. This report was primarily concerned with access to services. Although it had been anticipated that it would report palliative care need and actual services and therefore identify gaps, it highlighted the differences in data collection throughout the country and a lack of common definitions. It did however, provide a platform for identifying the work provided by primary care providers – general practitioners, aged residential care, district nurses, hospitals and home care services.

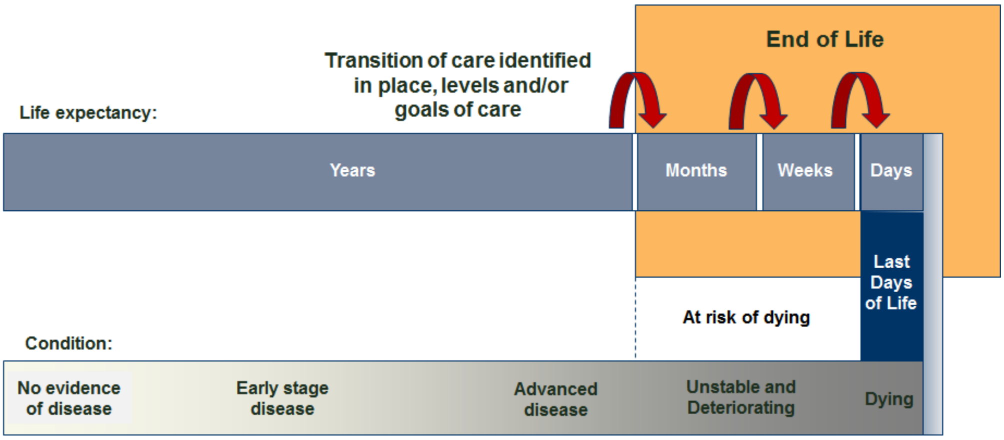
The Palliative Care National Service Plan for Adult Palliative Care (MOH, 2012) identified expectations for planners, funders, providers and the community to inform efficient and sustainable planning and funding directions around palliative care service provision. A hospital palliative care capability framework and hospice capability framework have also been outlined to build a description of services offered and the skill mix and experience needed to deliver these services (MOH, 2012).

Measuring What Matters (Palliative Care Council of New Zealand, 2012) is a document that established a framework that would generate data to monitor and evaluate the strategic development and direction of palliative care in New Zealand, and would replace the Palliative Care Strategy (MOH, 2001) as this was becoming increasingly out of date. It was to be useful as a whole system approach acknowledging that palliative care was being provided in a variety of settings such as aged residential care and primary care and not just in specialist services. Because a variety of services was being provided in a variety of ways it was difficult to measure how this was contributing to the overall aim.

In 2014 the Palliative Care Council of New Zealand developed referral criteria for adult palliative care that were relevant for specialist palliative care services, namely hospices and hospital palliative care services, and how these specialist services related to other providers by creating a more uniform understanding of palliative care provision across all settings. The MOH (2014) published Palliative Care and Māori from a health literacy perspective the same year, to gain insight into how Māori access to palliative care could be strengthened. This report acknowledged that health literacy for Māori in the palliative care context is a complex topic, but did provide helpful recommendations that support whānau, optimise quality of life, maintain mana, and enable preferred death experiences that give free expression to cultural values and practices relating to death and dying (p, xi).

Language/terms used in palliative care have been problematic over time with no internationally agreed consensus. This led discussion between the Ministry of Health, the Palliative Care Council and Hospice New Zealand to work jointly on a glossary that would be useful in the New Zealand context. Originally published in 2012, the glossary was updated in 2015 and should be viewed as a living document as definitions change over time (MOH, 2015). The inclusion of Māori terminology and diagrammatic representation in the glossary assists clarity. For example, following the text on end of life (p. 4), Figure 1 supports the descriptor in visual form.

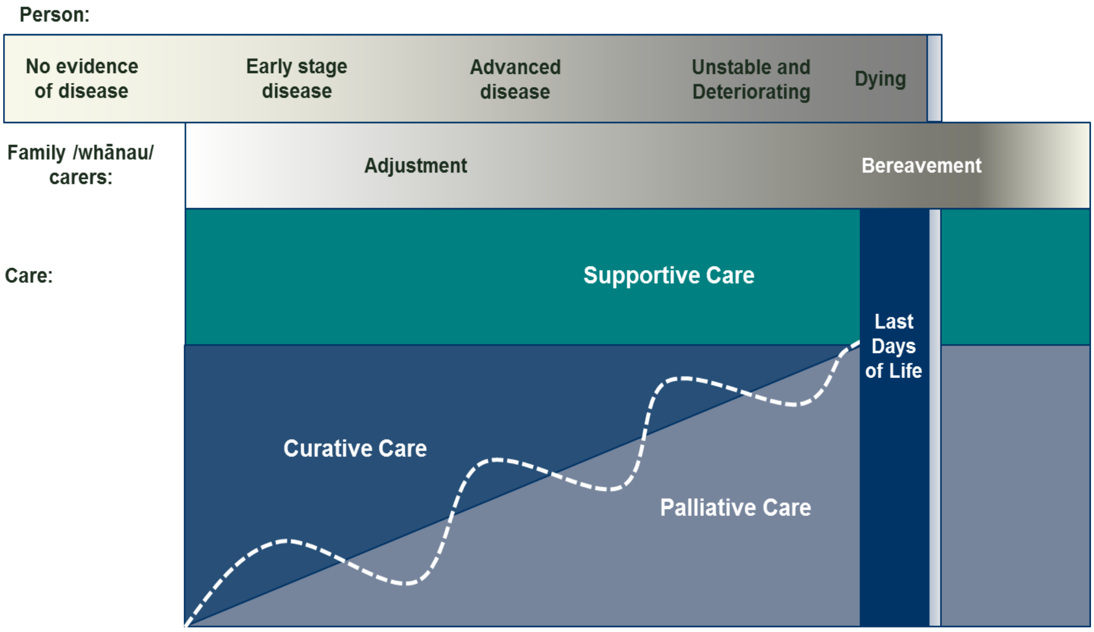
Figure 1: End of Life and Last Days of Life.



Note. From *New Zealand Palliative Care Glossary*, by MOH, 2015 (https://www.health.govt.nz/system/files/documents/publications/new-zealand-palliative-care-glossary-dec15.pdf). CC BY 4.0.

In explaining how palliative care fits within the continuum of health care, the diagram – Figure 2, (p. 13) provides a helpful visual to aid understanding.

Figure 2: Adjustment, Support and Palliative Care for Adults



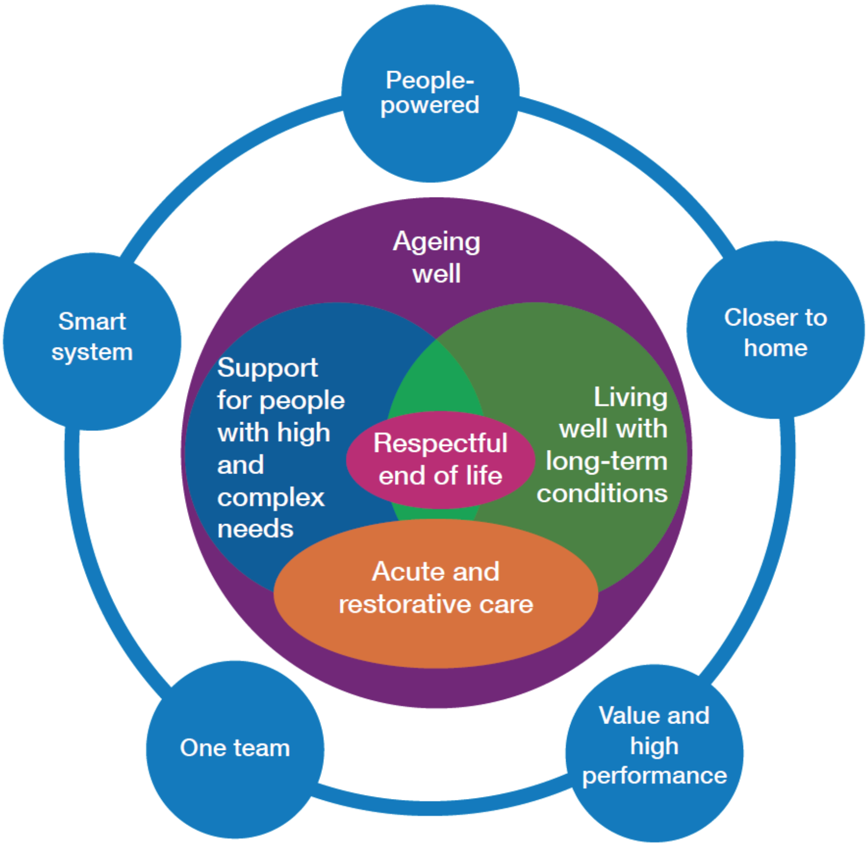
Note. From *New Zealand Palliative Care Glossary*, by MOH, 2015 (https://www.health.govt.nz/system/files/documents/publications/new-zealand-palliative-care-glossary-dec15.pdf). CC BY 4.0.

A review of adult palliative care services was undertaken from October 2015 to September 2016 which predicted that over the following 20 years the number of deaths in New Zealand was projected to increase from around 30,000 to around 45,000 each year, with many of these people likely to benefit from palliative care services (MOH, 2017). The Review of Adult Palliative Care Services in New Zealand, identified five priority areas reflecting the key themes arising from the review, to:

- increase the emphasis on primary palliative care
- improve quality in all settings
- grow the capability of informal carers in communities
- respond to the voices of people with palliative care needs and their families and whanau
- ensure strong strategic connections.

The timing of this review was also relevant in that the Associate Minister of Health (2016) released the healthy ageing strategy which aims to support older people to age well, make informed choices about their health and wellbeing and ensure a person-centred, responsive system. In particular, the strategy is about enabling people to feel safe and supported to openly discuss and plan for their end of life. These priorities are aimed at managing future demand and achieving the overarching goal to provide high-quality care, in all settings and geographical locations, enabling someone to die in an environment that feels, and is, safe and comfortable (MOH, 2017b, p. 2).

Figure 3: Strategic Framework for Healthy Ageing



Note. From *New Zealand* Healthy Aging Strategy, by the Associate Minister of Health, 2016 (https://www.health.govt.nz/system/files/documents/publications/healthy-ageing-strategy_june_2017.pdf) CC BY 4.0.

The Palliative Care Council has also undertaken various initiatives to address specific population needs of specific communities. These initiatives acknowledge the Māori model of health, Te Whare Tapa Whā (four-sided house) (Durie, 1985). The sides are: wairua (spiritual aspects), hinengaro (thoughts and feelings), tinana (physical aspects), and whānau (family and community aspects). If all of these aspects are nurtured, then harmony will be ensured, and there will be positive benefits to whānau ora - the overall well-being of the community. Other health perspectives, such as te wheke (the octopus) and nga pou mana (supporting structures), value connections with the environment and cultural heritage, with or without the aspects of Te Whare Tapa Whā

(Durie, 1998). These principles are central to culturally appropriate and safe palliative care.

Moeke-Maxwell et al. (2020) undertook a bicultural study with bereaved families reflecting on the end-of-life experiences of their elderly family members (over 80 years of age). 19 Māori and 39 non-Māori families' participated, sharing their experience of care across a range of settings including home, hospital, hospice, and aged residential care facilities. They utilised the Te Whare Tapa Whā framework to discuss examples of care across the four care domains, and found it applicable to both groups with respect to the need for holistic care across the domains of whanau, wairua, hinengaro and tinana. The interconnectedness of the framework was evident because when one of the domains was compromised, it affected the remaining three. When good care was articulated, all four domains had been attended to, whereas examples of less than ideal care reflected that one of the domains had not been adequately addressed. "When in balance, these four health domains act as pillars to support indigenous and non-indigenous older people at end of life, and their bereaved families before and following their death" Moeke-Maxwell, et al. (2020, p. 190): They propose a whare tapa whā older person's palliative care model to support the care of the dying older person and provide support to their family/ whanau.

Recognising that a competent and skilled nursing workforce was required to deliver palliative care, a National Professional Development Framework for Palliative Care Nursing Practice was developed by the Palliative Care and Cancer Nurses Education Group (PCNEG) in 2008 as part of the Ministry of Health's Cancer Control work programme. The overarching purpose of the Framework remains, as then: to improve the care of patients and families facing the problems of living with a life limiting condition by providing a framework to guide the development of a sustainable nursing workforce capable of providing high quality services. Palliative Care Nurses New Zealand (PCNNZ) remains invested in supporting New Zealand's nursing workforce, recognising the need for skilled nurses to enable quality and compassionate palliative care for both the individual and their family/whanau regardless of their diagnosis or place of care. PCNNZ views this Framework as a living document and undertook a review in 2014 (Palliative Care Nurses New Zealand, 2014). They were influenced by the National Health Needs Assessment for Palliative Care, phase 2 report (2013) highlighting the estimated growing need for palliative care. In addition, the Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (MOH, 2013) provided recommendations to inform planning and strategic development of palliative care services. Also, the Nursing Council of New Zealand workforce survey in 2012 identified 1423 nurses who reported that palliative care was one of their practice areas (two practice areas can be recorded). It was found that 914 nurses have palliative care as their main practice or employment setting, of whom 816 were registered nurses, 96 were enrolled nurses and two were nurse practitioners (Palliative Care Nurses New Zealand, 2014). These reports formed the basis of the 2014 update by PCNNZ, providing a framework to support nurses' professional development in palliative care. The competencies standards are utilised in the post graduate palliative care courses run at Canterbury University and Whitireia.

Te Ara Whakapiri: Principles and guidance for the last days of life (MOH, 2017c) was developed to support and promote quality care at the end of life for all adults in New Zealand across all health settings, and offers helpful examples of good practice, approaches and tools to assist practitioners. It includes:

- a baseline assessment and care-after-death checklist (Care in the Last Days of Life)
- ongoing plans of care (Ongoing Care of the Dying Person to be used in health care settings and Home Care in the Last Days of Life to be used in the person's home)
- the Recognising the Dying Person Flow Chart
- a list of principles for general medical management planning (Medical Management Planning – General Principles)
- the Bereavement Risk Assessment Tool
- a Discharge Checklist (for people going home to die)
- symptom-management flow charts (covering pain, agitation, delirium and restlessness, nausea and vomiting, excessive respiratory tract secretions and dyspnoea/breathlessness). (MOH, 2017c).

Hospice New Zealand (2019) provided the 4th edition of the Standards for Palliative Care to support continuous improvement in hospice services and they have been written with consideration to other service providers, to facilitate their use for their own improvements in end-of-life care.

Advanced Care Planning (ACP) has also gained momentum in New Zealand in recent years. Discussions began in New Zealand in 2010. The National ACP cooperative vision is that ‘all people in New Zealand will have access to comprehensive, structured and effective advanced care planning’. It is an opportunity to encourage conversations about what is important to individuals, and those closest to them and health providers regarding end-of-life care. The Health Quality and Safety Commission New Zealand (n.d.), in partnership with District Health Boards, support a national ACP day in April each year, previously known as ‘conversations that count’. ACP guidelines also reflect the New Zealand Code of Health and Disability Services Consumer Rights.

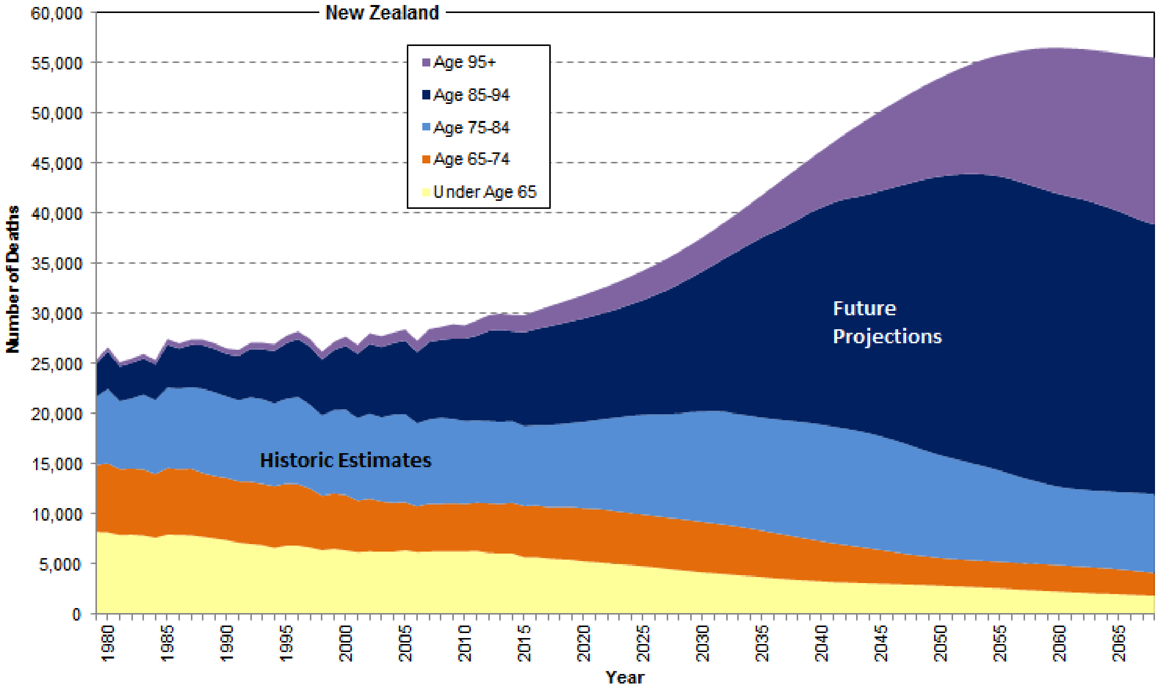
This section has highlighted a willingness to collaborate between government agencies and Hospice New Zealand in the provision of strategic documents to guide practice and service provision. Input from policy makers, clinicians, and funding agencies has provided supportive resources that are able to guide respective communities to meet the palliative care needs of their region. However, with limited finance attached to these initiatives, progress has been slow. Hospices are non-government organisations, largely reliant on District Health Board contracts to provide palliative care in their regional geographical locations, and although the regional funding differs, it amounts to approximately 70% of running costs (Groenevled et al., 2017). Hospital palliative care teams are funded from the hospital budgets. Funding is frequently based on historical allocation and lacks a clear rationale, although sometimes adjustments are made for population and service characteristics. The funding shortfall is frequently topped up through charitable donations and fundraising in local communities.

The Palliative Care Council, which had undertaken a range of significant projects since its establishment in 2008, providing independent advice to the Minister of Health on palliative and end-of-life care, was disestablished in August 2015. The MOH is now responsible for the update of these reports and it is hoped momentum will not be lost. Personal Communication with the former secretariat of the Palliative Care Council 9/9/2020 would suggest nothing has been achieved since the disestablishment.

An important piece of work undertaken by Heather McLeod (McLeod, 2016) at the Palliative Care Council was to look more closely at estimated future need for palliative care. This was influenced by Murtagh and colleagues (Murtagh, et al., 2014) in the UK who changed their methodology for data gathering and found the estimated need for palliative care at that time rose from the original 37% estimated need to 63% in England. Ireland and Germany applied the same methodology and also found the estimated need was more realistic (Kane, et al., 2015; Scholten, Gunther, Pfaff, & Karbach, 2016).

In applying this methodology McLeod (2016, Figure. 3) shows not only is there projected to be a large increase in the number of deaths each year in New Zealand, but the deaths are projected to be at much older ages. Note the increase in deaths age 85-94 and age 95+.

Figure 4: Predicted Increase of Deaths in New Zealand



McLeod (2016).

Figure 5: Predicted Deaths in New Zealand by age bands

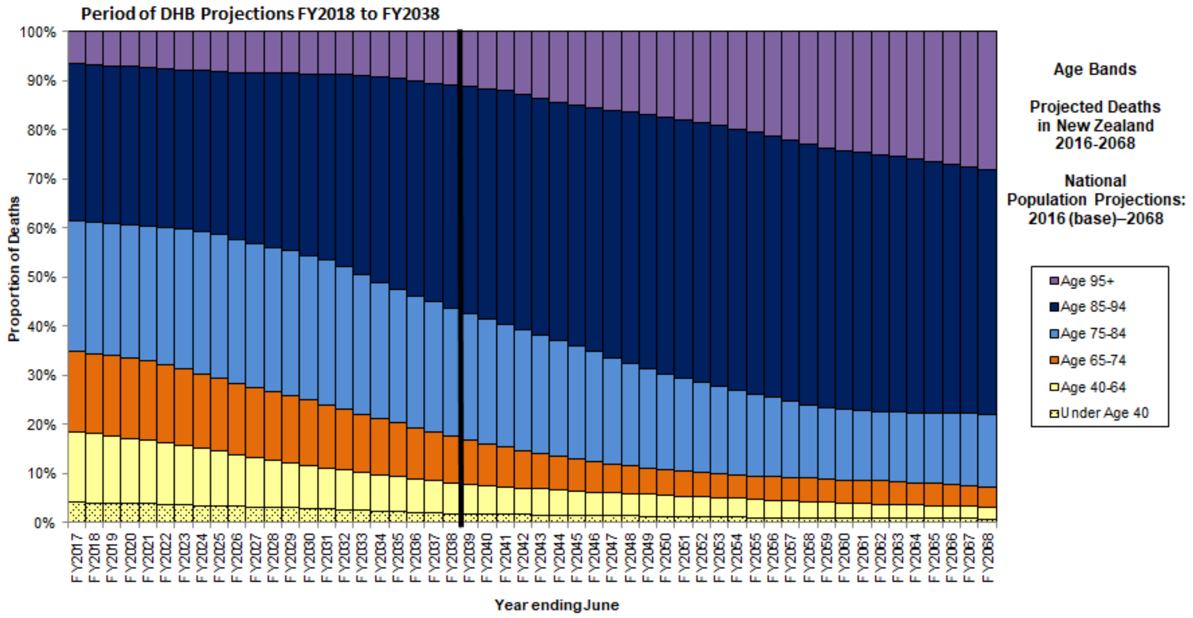


Figure 5 shows in 2017 there were projected to be 12,020 deaths at age 85 and over, which is 38% of total deaths and in the financial year (FY) 2068 the median projection is there will be 45,570 deaths age 85 and over, and these will be 78% of total deaths. The increase in deaths at age 85 and over is nearly fourfold (379% change).

Figure 6: Predicted Deaths by Age Bands

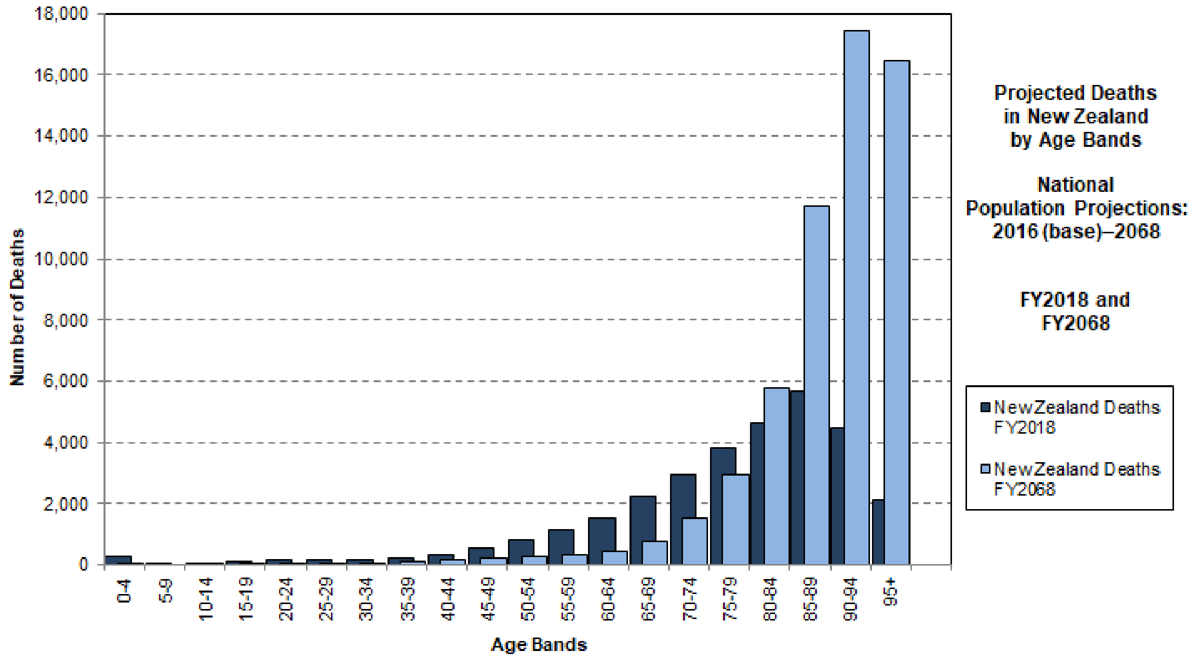


Figure 6 Suggests there are projected to be 31,600 deaths in FY2018 and 58,500 deaths in FY2068, an increase of 85%. The population is projected to increase by only 34% over the same period. The age bands at which the deaths occur are projected to be much older by the end of the period (McLeod 2016).

Figure 7: Cause of Deaths in New Zealand 2000-2013 obtained from Ministry of Health MORT Data

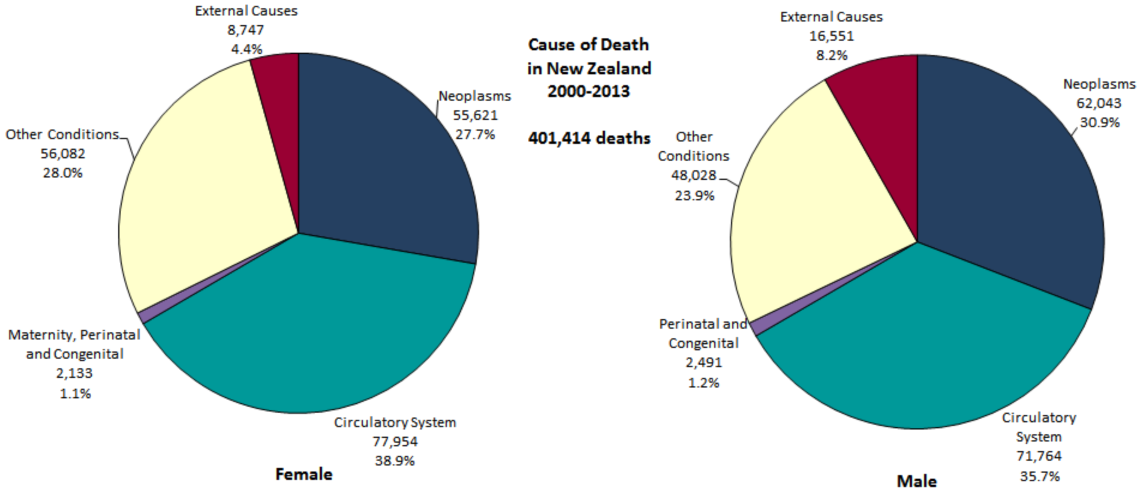
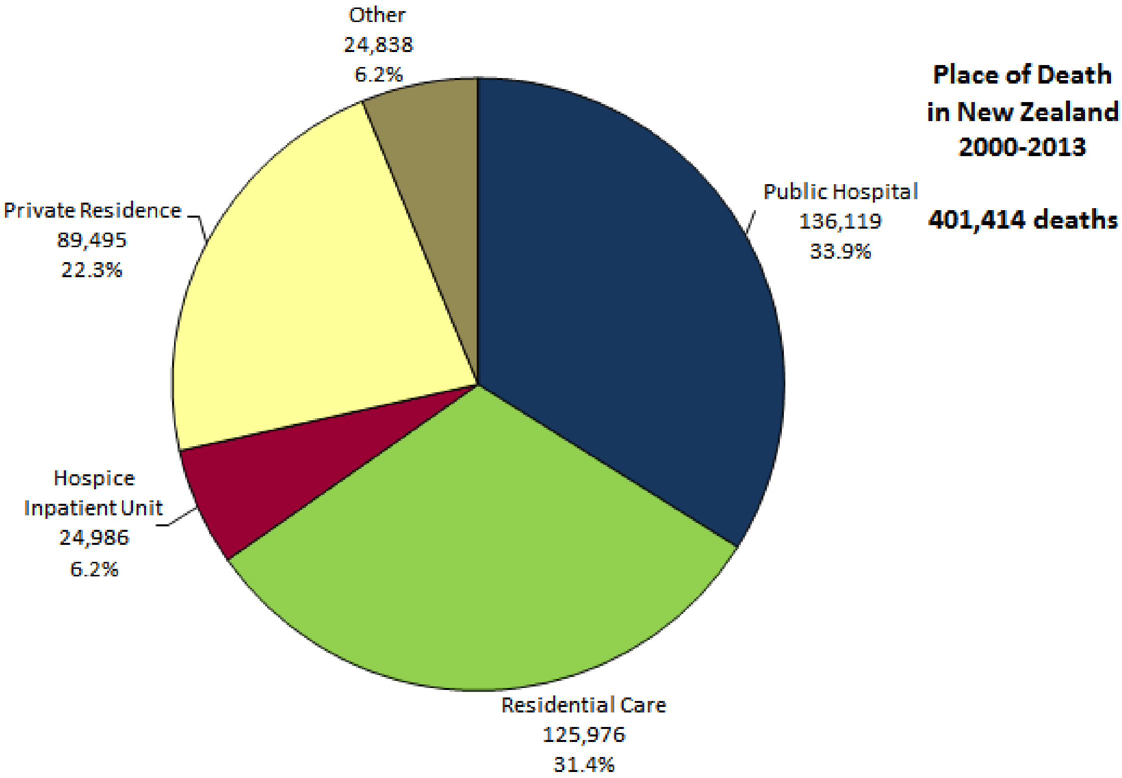


Figure 7 shows proportionately; more men die of external causes and slightly more men die of neoplasms. Proportionately, more women die of circulatory system and other conditions (McLeod, 2016).

McLeod's (2016) data indicates the cause of death in older age groups is predominantly from circulatory and respiratory illness, dementia and frailty, rather than cancer, and that these people may benefit from access to palliative care services.

Figure 8: Place of Deaths in New Zealand 2000-2013 obtained from Ministry of Health MORT Data



(McLeod, 2016).

The mortality data only includes Hospice patients whose place of death was in the Hospice inpatient unit, and therefore does not provide a reliable indication of all those receiving Hospice care, as it does not consider those involved with community services attached to hospices. McLeod (2016) shows that in the year to June 2015, 74% of hospice patients had no admission to any hospice inpatient unit. Hospice New Zealand reports that only 23% of hospice patients died in a hospice IPU, while 69% of deaths were in the community, either at home or in aged residential care.

This work highlights the major challenge for palliative care in future will be that, not only will the number of deaths be increasing, but they will be increasing in older age bands. Deaths are likely to be occurring among people with more co-morbidities and a high prevalence of dementia. If current patterns of end-of-life care continue, most of these deaths over age 85 will occur in residential aged care facilities after an extended period of care. This will challenge not only the existing models of care but also the way end of life care is funded. The death data however only shows part of the story. The data do not show how often palliative care was involved, nor at what level, as palliative care is not only about caring for the dying, “Palliative care is provided according to an individual’s need, and may be suitable whether death is days, weeks, months or occasionally even years away” (MOH, 2015). For many people, their place of care moves between different facilities during their final year of life and may include home (private residence), hospice, hospital, and aged residential care facilities. Palliative care delivery can also fluctuate between primary care, district nursing, hospice services, and hospital palliative care teams. There has been no study undertaken to date to monitor these transitions in care and assess their appropriateness. The best to date has been research undertaken in Auckland, looking at the movement between aged residential care and the public hospital service (Boyd et al., 2009; Boyd et al., 2011; Broad et al., 2013).

This section has shown willingness and collaboration between New Zealand agencies to guide service provision, professional development, definitions and workforce directions. Despite this there is a tide of discontent amongst palliative care health care providers, and mounting pressure on how to provide services with increasing demand. This pressure is experienced personally and professionally. When students of all disciplines gather together to undertake the post graduate education in palliative care that I facilitate, I am increasingly aware of the burgeoning demands on their respective services around the country. The demands are multifactorial, but they come united with concern about how to juggle expectations of their respective organisations and what they assess as being necessary for those they are caring for, the recipients of their care. During my research journey, I have cared for friends and family members who have been recipients of palliative care services, and witnessed this pressure from personal experience. Acknowledging this unease, turning to research to explore the issues further, was a catalyst for this adventure.

This research proposes a time to pause, and with respect for the past 20 years of strategic planning, asks, are we heading in the right direction? Are these guiding documents to service provision and care what the receivers of the service need? And what are the views of those at the bedside (family, health professionals and volunteers) as to our community’s future direction in end-of-life care? Whilst the policy makers seek input from front line staff, there is often limited response to requests for feedback, and even less attention paid as to how these documents are integrated into practice. Respecting the impressive amount of work undertaken to date from the ‘top down’, it is proposed in this research to complement that work by working from the ‘bottom up’, engaging in dialogue with consumers of services, and palliative care service providers at the ‘coal face’, to gauge effectiveness and search for meaningful ways of providing end-of-life care. This is respectfully suggested in the hope of meeting in the middle with supportive ways of engaging with the community’s needs for the future.

This chapter has revisited the early beginnings of end-of-life care from an international perspective, where the British history, and the pioneering work of Cecily Saunders at St Christopher’s Hospice influenced the beginning of the hospice movement in New Zealand. The guiding principles and strategic documents are acknowledged and future demographic predictions presented for consideration, raising awareness of potential demands on services for the future. The next chapter will discuss the methodology chosen to undertake this research.

Chapter 3 Methodology

> “I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me understand?”-James P. Spradley

The previous chapter offered an historical overview of the early beginning of end-of-life care in New Zealand, addressed the demographics ahead, and suggested a time to pause to consider what is important for the journey ahead to meet the needs of those we serve. In this Chapter I discuss the philosophical and theoretical framework that underpins the design of this research and has guided me through the method for conducting the research.

To undertake research in this area, to unfold a realistic and respectful way forward, I relied on the practice stories of the front-line health professionals – predominantly palliative care nurses and doctors, who have been journeying with the dying, and the stories of the patient and family. It also sought opinions from consumers of palliative care services and volunteers who contribute significant hours of support to their dying community members. This study was sought as a way of acknowledging and understanding. It therefore required a human science approach that reveals the ontological perspective of participants.

Phenomenology denotes interest in people making sense of their world as they experience it. It acknowledges that people are influenced by all their experiences in the world from birth, and that we are all shaped by a long cultural history (Benner & Wrubel, 1989). It is so integrated that we do not always know why or how we do or think about things. Phenomenology relates to the ontological question “what is being?”, and to the epistemological question “how do we know?” (Ray 1994).

This research aimed to explore, describe and conceptualise the wishes and needs of the person who was dying and their family, and explored the lived experience of the health professionals involved in palliative care, by describing, identifying and portraying their perspectives. By exploring both those who give and receive care at the end of life, it was anticipated that uncovering practice wisdoms may assist in shaping the way forward, to meet the needs of our community. It also aimed to seek the lived experiences and uncover the reality of delivering palliative care according to the WHO and MOH philosophy of care within the community.

Empirical/analytical methodologies that concentrate on observation, measurement, categorisation and classification cannot provide this sort of understanding, as their ontological and epistemological positioning is not focussed on the social construction of the lived experience. This chapter will therefore illustrate the way in which hermeneutic phenomenology provides an appropriate methodological framework on which to base this study.

In phenomenology and nursing there is a belief that people are whole and inseparable beings who are self-interpreting and have the ability to control their own destinies (Omery, 1983; Taylor, 1993). The aim of hermeneutic phenomenology is to understand a phenomenon from the perspective of the person who experiences it. In much the same way, health care professionals are ultimately concerned with the health and illness experiences of people as they experience them (Oiler, 1982; Taylor, 1993). They gain much of their knowledge through listening to, reflecting on and sharing, the experiences of the people they care for. These experiences, however, are limited by opportunity. Therefore, other ways of learning from lived experiences must be recognised. Hermeneutic phenomenological research provides nurses, doctors and other health professionals with insight into the personal experiences of illness and dying.

The research question for this study also required a methodology that creates knowledge, which can then be readily applied to nursing and medical practice. Van Manen (1990) refers to hermeneutic phenomenology as a “critical philosophy for action” (p.154). He suggests, “hermeneutic phenomenological reflection deepens thought and therefore radicalises thinking and the acting that flows from it” (p.154). This type of research has the potential to encourage a stance of thoughtfulness, which will in turn motivate health professionals to think critically and reflectively, to challenge and improve their practice and therefore, provide care that is appropriate, respectful and achievable within the context of current demands. It is a methodology that “invites us to revisit our conscious experience and open ourselves to the emergence of new meaning, or at least the authentication and renewal of present meanings” (Barkway, 2001, p. 192).

Phenomenological research is the practice of creative insight that has to do with beginnings: the historicity of the beginning of beginnings where meaning originates. A phenomenology of ‘creative’ insight would challenge us to find our way back to the beginning where the beginning must be sought by the primordiality of lived experience rather than theory (van Manen, 2014). This is an invitation to revisit the early beginnings of phenomenology as a methodology and a method, as well as the early beginnings of palliative care where the understandings can lead to creative insights for the way forward for the human experience of dying.

According to van der Zalm and Bergum (2000), “although interpretive inquiry, such as hermeneutic phenomenology, does not prescribe action for use in clinical practice, it does influence a thoughtful reflective attentive practice by its revealing of the meanings of human experience” (p. 211). Respectfully listening to the participants’ story, we give voice to the less articulated yet important aspects of those living with dying, as discussed by Coyle (2006), Dunniece and Slevin (2002), Watson, (1999, 2006, 2008b, 2011), and Johns (2004, 2006, 2008).

Using a phenomenological methodology informed by van Manen and Heidegger, this research incorporated unstructured audio taped interviews undertaken in two parts, one being with people receiving palliative care or families who have lived the palliative care experience, and the other with health care professionals who provide palliative care services. This chapter will concentrate essentially on my interpretation of phenomenology underpinned by the writings of Heidegger and van Manen, as they apply to this research.

Introduction to phenomenology

Phenomenology is a philosophy, a philosophical approach, and a research method that is concerned with the meaning of human experiences. Palliative care is also a philosophy, a philosophy of practice, concerned with living as well as possible until death. This creates a synergy between research methodology and practice.

Phenomenology is considered one of the most important philosophical movements of the twentieth century. Edmund Husserl and Martin Heidegger are acknowledged as launching the phenomenological movement but both acknowledge the work of Edith Stein (empathetic and faith phenomenology), Max Scheler (personalistic and value phenomenology) and Jan Patočha (personal practice phenomenology) as original thinkers contributing to this ground-breaking work (van Manen, 2014).

Phenomenology originated in the 1890s with the work of Edmund Husserl, who focused on the epistemological question of: "How do we know what we know?" (Ray, 1994, p.118). Heidegger, a student of Husserl, further developed phenomenology by focusing on the ontological question: "What is being?" (Ray, 1994, p.118). Other philosophers who have written about phenomenology such as Gadamer (1975/1996), Merleau-Ponty (1962), Sartre (1956,/1968), Ricoeur (1981) and van Manen (1990), have each added their own interpretations, refuting and extending on each other's thoughts. Van Manen (2014) also acknowledges the group of scholars, although now dead, who pushed phenomenology in a variety of helpful directions that are still utilised today. These are Levinas, Sartre, de Beauvoir, Gadamer, Ricoeur, Blanchot, Bachelard, Schutz, Arendt, Henry, and Derrida (van Manen, 2014). Although common threads exist between each scholar's views, no two approaches to phenomenology are identical. This research acknowledged the early work of Husserl, and is underpinned by Heideggarian phenomenology, and van Manen's various writings (1990, 1997, 1998, 1999, 2014) are used as the practical guide.

Edmund Husserl and Martin Heidegger

Edmund Husserl is generally regarded as the intellectual founder of phenomenological philosophy. As a mathematician, he was disillusioned with scientific methods of investigation created by the natural sciences and out of interest and curiosity he attended lectures on psychology and philosophy and became so fascinated that he set out to define a philosophy that restored science's contact with what he described as the "deeper human concerns" (Cohen & Omery, 1994, p.138). He defines phenomenology as a descriptive philosophy of essences of pure experiences, aiming to capture the experience in its primordial origin without interpreting or explaining or theorising. The essence of lived experiences:

> It is plain that I, as someone beginning philosophically, since I am striving toward the presumptive end, genuine science, must neither make nor go on accepting any judgement as scientific *that I have not derived from evidence*, from “experiences” in which the affairs and affair-complexes in question are present to me as “they themselves”. (Husserl, 1999, p. 13)

In his early text, *Ideas Pertaining to a Pure Philosophy and to a Phenomenological Philosophy*, he labours the point that phenomenology does not concern itself with facts or realities in the way psychology does. Rather phenomenology wants to establish itself, “not as a science of matters of fact, but a science of essences; it . . . exclusively seeks to ascertain “cognitions of essences” and no “matters of fact” whatsoever”. (Husserl, 1983, p.xx).

Husserl’s beliefs were consistent with the Cartesian tradition and therefore he was interested in the way the world is experienced through consciousness. His interpretation of phenomenology came to be known as ‘transcendental phenomenology’. Husserl’s work was primarily concerned with questions of epistemology or knowing. His overall aim for research was “…the avoidance of all conceptually bound and theoretically constructed beginnings” (Ray, 1994, p. 119). He introduced the concept of ‘lived experience’ using phenomenology as the methodology to study ‘experience’ as the ultimate meaning of knowledge. Husserlian phenomenology according to Koch (1995) came to mean the study of phenomena as they appeared through consciousness (p. 928) and assumed a mind-body split, a Cartesian duality. Husserl wanted to bring light to the ultimate structures of consciousness or essence and to critically evaluate the role these structures play in making sense of things. He reasoned that these essences could be isolated and studied objectively. The phenomenological question can be answered by the process of phenomenological reduction by which all preconceived notions are eliminated. This is referred to as’ bracketing’ and according to Koch “defends the validity or objectivity of interpretation against the self-interest of the researcher” (1995, p. 829).

Martin Heidegger began his career in Germany as a student of Edmund Husserl, and is widely considered as the most significant and gifted philosopher of the twentieth century. He has influenced the thinking of all subsequent major philosophers, and his thinking has been formative for developments in the human sciences, arts, humanity, social theory, technology and computer science (van Manen, 1990).

At a time of major unrest in Europe with war and philosophical challenges, Heidegger believed that a person's background is informed by the culture in which they live and this presents a way of understanding the world. Since these cultural meanings and practices are already in the world before we understand, they are "pre-understandings" and are a structure of our being in the world. It is not something that can be bracketed out or eliminated. As individuals, we live in the world, we are constructed by this world and in turn construct this world from our own experience and background (Heidegger 1993, p. 22).

In contrast to Husserl's epistemological focus, Heideggarian phenomenology focuses on questions of ontology or what it means 'to be'. Fundamental to Heidegger's philosophy is the rejection of Cartesian duality. Heidegger (1927/trans. 1962) disagreed that one could separate the person from the world. He argued that 'as a person, I am already in the world and therefore I cannot be separated from it'. Other researchers such as Leonard (1994) and Crotty (1996) have discussed and reflected on Heidegger's approach. Leonard (1994, p. 47) notes that Heidegger makes reference to "our being 'thrown' into a particular cultural, historical and familial world". Despite this being 'thrown' into a predetermined world, people have the ability to make choices about the way they live (Crotty, 1996). Heidegger denotes that before we can understand how we experience the world, we must first understand what it means to be a person (Leonard, 1994). Heidegger uses the German word 'Dasein' or 'being there' to refer to the kind of being that is capable of reflecting and inquiring about the meaning of his/her own existence (Gelven, 1989). Such being exists in a historical sense; it is communicated in language, which is historically driven. As our being is located within the past and the here and now, it cannot be abstracted and we co-exist as humanity, we share meaning and an understanding of the world and its practices. Heidegger defined this phenomenon as "the clearing" (Heidegger; 1962/1927 as cited in Plager, 1994, p. 69).

Another essential concept in understanding Heideggerian phenomenology is the notion of care. Heidegger suggested that in our being in the world, we care. To care is to render things as mattering, being meaningful and having significance (Gelven, 1989). This concept of care is congruent with the nursing paradigm, which embraces caring as a central concept, referring to it as the profession's "moral ideal" (Watson, 1985, p. 29) and as the very "essence" of nursing (Leininger, 1988). The New Zealand Nurses' Organisation (1993) expresses this relationship in their social policy statement defining nursing as "a specialised expression of caring…" (p. 2).

Heidegger (1927/1962) based his understanding of phenomenology on the etymological origins of the word's two components, phenomenon and logos. The word 'phenomenon' originated from a Greek verb meaning "that which shows itself in itself" (Heidegger, 1927/1962, p. 54); 'Logos' means discourse or more specifically, "making manifest what one is talking about" (p.56). In Heideggerian terms phenomenology, as a branch of research, means "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (Heidegger, 1927/1962, p. 58). Gelven (1989), in his commentary of Heidegger's work, translates this into a more comprehensible definition of phenomenological research:

> Analysis by which the meaning of the various ways in which we live can be translated from the vague language of everyday existence into the understandable and explicit language of ontology without destroying the way in which these meanings manifest themselves to us in our everyday lives (Gelven, 1989, p. 42).

Heidegger (1927/1962) defined a phenomenon as "something that proximally and for the most part does not show itself at all: it is something that lies hidden" (p. 59). He goes on to say "covered-up-ness is the counter-concept to phenomenon" (p. 60). Heidegger (1927/1962) suggests that phenomena can be covered up in various ways. Firstly, phenomena can be "undiscovered" or not known (p. 60). Alternatively, a phenomenon once known can become "buried over" or it can become "disguised" (p. 60). The task of phenomenology is to uncover or "lay bare" these phenomena (p. 60). This uncovering or understanding is achieved through hermeneutic interpretation.

Hermeneutics

Heidegger introduced the practice of hermeneutics to phenomenology. In Greek the verb *hermeneueuein* means 'to interpret' and it was from here that the word hermeneutics originated (Thompson, 1990). Prior to this usage the Greek name Hermes was attributed to the mythological messenger of the gods (Gaarder, 1995). Hermeneutics was adopted by theology and used to refer to the theory and practice of interpretation of biblical and legal texts (Thompson, 1990). Recognised in the Western world as an important challenge to the contribution of positivism, hermeneutics rejects empiricist accounts of science on the grounds that all human life unfolds in a context of shared meaning. Although there are differing schools of hermeneutic thought, common to all hermeneutic inquiry is a focus on understanding and interpretation as processes (epistemology) and modes of being (ontology) (Reeder, 1988).

Hermeneutics, as Heidegger describes it, refers to the circular manner in which we interpret meaning (Heidegger, 1927/1962). He explains that because we have a background of shared experiences we do not begin our quest for understanding without some prior knowledge or experience. Rather, we begin with a pre-existing level of understanding; he calls this the “forestructure” of understanding (Heidegger, 1927/1962, p. 195). This forestructure of understanding is divided into three parts. The ‘forehaving’, being the familiarity or knowledge one already has; the ‘foresight’, the point of view one has already considered and finally the ‘fore conception’, one’s conceptualisation of the expected interpretation (Gelven, 1989; Heidegger, 1927/1962; Leonard, 1994; Plager, 1994). It is this process of understanding that Heidegger refers to as the ‘hermeneutic circle’. Within the circle the researcher moves from the initial ‘forestructure’ or pre-understanding to what is being revealed in the research. In this research I entered the hermeneutic circle with my pre-understandings of being a palliative care nurse and a researcher. From this position I moved forward and my understanding was transformed by the lived experience descriptions provided by colleagues as participants, and by the lived experience of the consumers of palliative care services through interviews and generated texts.

In his philosophical writings Heidegger presents a way of understanding how we find ourselves in the world, how we live with others and how we make meaning of our lives and our existence as a whole. His ideas though, are not easily absorbed, in part because of language where he uses new terms in order that we might comprehend things in a new way. There is also a difficulty when relying on translation of his German work where his neology loses some of its nuances. As a result, some of his ideas have been regarded as inspired, whereas others see them as trivial and vacuous (Steiner, 1978). Heidegger was considered the most important German academic philosopher of the twentieth century but he was also controversial as a member and supporter of Hitler and National Socialism and there have been debates in the literature as to whether he was anti-semitic. Luft (1994) offers an interesting historical review of Heidegger and states that “scholarly work since 1987 has done a great deal to enhance the possibility of a balanced view of Germany in the 1930s and of Heidegger’s relationship to it”. (p. 501).

Despite the controversy, Heidegger’s explanation of what it means to be in the world links appropriately with health and illness, and his work is central to modern philosophical thought, and was relevant to my enquiry. He explains that although science aims to investigate an intended object of its enquiry, there are times where the theoretical explanations cloud the way the enquiry is framed and therefore colours the answer obtained. Toombs (1987) writes of this highlighting the way in which presuppositions and a different focus of understanding unfold:

> In discussing my illness with physicians, it has often seemed to me that we have been somehow talking at cross purposes, discussing different things, never quite reaching each other. This inability to communicate does not, for the most part, result from inattentiveness but from a fundamental disagreement about the nature of illness. Rather than representing a shared reality between us, illness represents in effect two quite distinct realities, the meaning of one being significantly and qualitatively different from the other. (Toombs, 1987, pp. 219-220)

Toomb’s explanation highlights a different perspective held by physician and patient, which is understandable in terms of Heidegger’s explanation of what it means to be in the world. The physician sees the signs and symptoms of the illness leading to a diagnosis of an illness, whereas the patient experiences the effects of illness on their everyday life. To presume that either world view is correct is to negate Heidegger’s argument. Rather, both positions simply reflect the nature of human existence and involvement in the world.

Hermeneutic phenomenology is a human science which wishes to meet human beings where they are naturally engaged in their world (van Manen, 1997). It “edifies the personal insight contributing to one’s thoughtfulness and one’s ability to act towards others” (p. 7). The endeavour in hermeneutic phenomenology is to show the meanings that arise out of the lived experiences, in order to gain insight and deeper understanding into a particular phenomenon (Jones & Chapman 2000, p.155). Van Manen (1997) notes that a full and final description using hermeneutic phenomenology is impossible, that the researcher must be cognisant of the fact that lived life is always more complex than an explication of meaning can reveal. Van der Zalem and Bergum (2000) concur, suggesting that the results of phenomenological inquiry are descriptive in nature, depicting many possible experiences.

Max van Manen

A framework developed by Max van Manen was used as a practical guide in carrying out this research. Van Manen is an Emeritus Professor of Education at the University of Alberta, Canada, with a particular orientation in pedagogy. Van Manen (1990) provides a guide to undertaking phenomenological research based on an eclectic combination of traditional and contemporary phenomenological works. His phenomenological approach is said to be a blend of “Husserlian and Heideggerian philosophical underpinnings…” (Plager; 1994 p. 78); reflecting a background in the Dutch (Utrecht school) and German philosophic traditions. The research method: “…clearly articulates the relationship of phenomenology, hermeneutics, semiotics, and a research process of textual reflection that contributes to understanding practical action” (Ray, 1994). Thus, it interrelates description, interpretation, language, and the research process of considering ‘lived experience’, integrally linking the results to everyday living – the human experience.

Van Manen (2006) suggests phenomenology as a method for research has undergone many shifts, orientations or approaches and offers the following four classifications:

Transcendental phenomenology, presented by Husserl, Fink, Tymieniecka, van Breada and Giorgi as an interpretive rather than objective mode of description. It explores the way knowledge is based on insights rather than objective characteristics which constitute meaning.

Existential phenomenology, supported by Heidegger, Satre, de Beauviour, Merleau-Ponty and Marcel, who believe that the observer cannot separate themselves from the lived world. “Being in the world” is reality as it is perceived, and there is reciprocity of relationship between observer and the phenomenon, this constitutes human reality.

Hermeneutical phenomenology, Heidegger, Gardamer, Ricoeur and van Manen believe knowledge comes into being through language and understanding. Interpretation and understanding are intertwined and evolving processes. Culture, art and poetry are often used in this form of interpretation.

Linguistical phenomenology, supported by Blanchot, Derrida and Foucault, takes the perspective that language and discourse reveal the relations between understanding culture, historically, identity and human life. Meaning resides in language and text rather than the subject, in consciousness or even lived experience.

There are two major assumptions that underpin phenomenology. The first being that perceptions present us with evidence of the world, not as it is thought to be, but as it is lived. And the second assumption is that human existence is meaningful, and of interest in that we are always conscious of something. Existence as ‘being in the world’ is a phenomenological phrase acknowledging that people are in their worlds and are understandable only in their contexts. Human behaviour occurs in the context of the four classifications noted above: relationships to things, people, events and situations (van Manen, 2006). In 2014 van Manen published his book, *Phenomenology of Practice*. He adopted the phrase ‘phenomenology of practice’ to describe the development and articulation of meaning-giving, practical examples of phenomenology. A phenomenology of practice sees new thinking as an “openness”, to be intrigued by the constantly renewing and creative impulses of the search for the experience and origin of lived meaning, and the meaning of meaning in human life (p. 213). This positioning suggests that phenomenology is not only sensitive to the concerns of professionals in practice but also to the personal and social practices of everyday living. It also acknowledges that life as we live and experience it can be rational and logical but also contradictory, mysterious, inexhaustible and full of existential and transcendent meaning that can only be lived out through aesthetic and ethical language.

Hermeneutic phenomenology is the study of human experiences wherein the aim is to understand the very essence and meaning of those experiences. This research method seeks to develop an understanding of lived experiences in a primordial sense from the immediate or pre-reflective position. This is the individual's immediate experience rather than the experience after it has been reflected on, theorised or conceptualised (van Manen, 1990). Van Manen suggests that, in order to achieve this the researcher must understand the process of phenomenological reduction.

Phenomenological reduction

Phenomenological reduction is the technique by which the phenomenologist constantly examines and confronts his/her assumptions, pre-understandings, feelings, theories and beliefs that may influence the way a phenomena is interpreted. Reduction is a way of getting close to the actual experiences or phenomena as they are lived. Phenomenological reduction, in the context of this research, is not to be confused with the term 'bracketing' as it is understood in Husserlian phenomenology. Husserl believed that the researcher must completely eliminate his/her prior knowledge or preconceptions about the phenomenon. Van Manen's eclectic guide to reduction disputes that complete reduction is neither desired nor possible. As Koch (1996) explains, the concepts of bracketing and hermeneutics are in fact "mutually exclusive" (p. 177). Fusion is considered part of the hermeneutic process and can be described as "the coming together of different vantage points", that of the researcher and the participants (Koch, 1996, p. 177). In fusion, the researcher "must be able to tolerate the ambiguity of relaxing (not eliminating) one's own preconceptions" (Thompson, 1990, p. 246).

Van Manen (1990) distinguished five levels of 'reduction'; heuristic, hermeneutic, phenomenological, eidetic and methodological. These levels of reduction are practised concurrently rather than as a sequential set of rigid procedures. In practising **heuristic reduction**, the researcher looks at the phenomenon with a clear mind, taking nothing for granted. Van Manen refers to this as the attitude of wonder, the willingness to step back and let things speak to us in their own terms. **Hermeneutic reduction** requires the researcher to explore and set aside his/her own pre-understandings, interpretations, beliefs and values regarding a phenomenon. In making these personal preconceptions explicit they are less likely to cloud or distort the phenomenon, ensuring it is interpreted as it is lived. Hermeneutic reduction also assists in ensuring the researcher is open to exploring all possibilities of meaning. **Phenomenological reduction** ensures that all existing theories, conceptualisations and scientific frameworks are set aside. In doing this, meaning emerges from concrete descriptions of lived experience rather than from abstractions or theories. **Eidetic reduction** asks the researcher to consider what it is about the phenomenon that makes it different from other similar experiences. This act of contrasting and comparing assists in illustrating the uniqueness of the phenomena being studied. Finally, **methodological reduction** is the intentional avoidance of ritualistic techniques in the design of the research. Phenomenology requires the researcher to creatively choose a design that will convey the meaning of the experience to the reader in an authentic and evocative manner.

These five levels of phenomenological reduction assist the researcher to see the world in an immediate and primitive manner. Merleau-Ponty (1962) describes the aim of reduction as assisting the researcher to discover “a direct and primitive contact with the world” (p. vii). Phenomenological reduction according to van Manen (1990) is the very core of phenomenology, allowing the researcher to become attentively aware of the things of the world as they are immediately experienced.

Methodological activities of hermeneutic phenomenological research

Van Manen (1990) outlined six methodological activities that can be used as a framework for phenomenological research. He emphasises this is not a rule bound process, whereby one step is completed before moving on to the next. Rather, the methodological activities are used as a guide and the researcher moves back and forward, completing each activity intermittently or at the same time, depending on how the emerging themes develop.

1-Turning to the nature of lived experience

Phenomenology is described as a human science, as it is specifically concerned with existential or lived experiences. It is only through our consciousness that we experience being in the world. Van Manen (1990) suggests the aim of phenomenology is to:

> transform lived experience into a contextual expression of its essence (meaning), in such a way that the effect of the text is at once a reflexive

> re-living and a reflective appropriation of something meaningful, a notion by which a reader is powerfully animated in his or her own lived experience (p. 27).

Turning to the nature of the lived experience requires a deep thoughtfulness and questioning of the phenomenon being studied. This involves identifying the issue of concern, that is, “what are the wishes and needs of the person who is dying and their family” and “what is the essence of the lived experience of the health professionals involved in palliative care?” The idea of turning to the nature of lived experience incorporates the premise that all human experience is situated in context. The word “situated” is a Heideggarian term that is “used to elaborate upon the contextual nature of human experience, for it to be ‘situated’ conveys the view of the person as being thrown into a world that circumscribes their choices and creates their possibilities” (Leonard, 1989, p. 44).

2-Investigating experiences as they are lived

Van Manen (1990) recommends that the researcher use personal experiences as a starting point in beginning a phenomenological study. He describes any phenomenon as a “possible human experience” and suggests, “one’s own experiences are the possible experiences of others” (p. 58). This observation implies phenomenological descriptions are intersubjective experiences that are universal in nature. The process of reflecting on personal experiences also assists the researcher to orientate to the phenomenon in question.

In order to comprehend the meaning of lived experiences, the researcher must first gain access to personal accounts or descriptions of these experiences. These personal accounts can be obtained through writing, interviewing, observation, experiential descriptions in literature, biography, journals, art and other phenomenological writing (van Manen, 1990). This research will predominantly rely on recording conversations to gather lived experience descriptions. Phenomenological interviews may be carried out simply to gather information about the experience (conversational interviews) or, in addition, to provide an opportunity for the interviewee to reflect on their experiences (hermeneutic interviews). Another preparatory technique suggested by van Manen (1990) is that of studying the words, idiomatic phrases and etymological origins that are associated with descriptions of the phenomenon. He suggests that valuable clues embedded in these descriptions may be uncovered within this process, assisting with interpretation and thematic analysis.

3-Hermeneutic phenomenological reflection/ thematic analysis

The aim of hermeneutic phenomenology is to gain an understanding of the essence of human experiences. This essence is quite different from our pre-reflective or 'taken for granted' understanding. In order to understand and articulate this type of meaning the researcher must undergo a process of reflection. This reflective process of explicating meaning is termed thematic analysis (van Manen, 1990). In hermeneutic phenomenology, thematic analysis is not merely a stage in the research process whereby the data are collated and categorised. It is an ongoing process that requires constant attentiveness to the text.

Van Manen (1990) refers to themes as the "structures that make up the experience" (p.79). The purpose of identifying these themes is to assist the researcher to structure the text. In identifying themes, the researcher endeavours to identify those things that stand out as 'telling' within the data. Themes are only a part of the entirety of the whole-lived experience or in van Manen's (1990) words they are "only fasteners, foci or threads around which the phenomenological description is facilitated" (p. 91). As the researcher identifies the themes, they are woven together to illustrate the essence or nature of the experience.

4-Hermeneutic phenomenological writing

Van Manen (1990, p. 131) emphasises that to be "able to do justice to the fullness and ambiguity of the lived experience, writing often turns into a complex process of re-writing, reflecting and reorganising." He suggests that the aim of hermeneutic phenomenology is "to transform lived experience into a textual expression of its essence" (van Manen, 1990, p. 36). The intention is that the reader will be drawn into the text almost as if entering into dialogue with it. The words and sentences will resonate with the reader's experiences so he/she can begin to see what it means to live these experiences. Van Manen (2016), talks about the challenge of avoiding objectifying, and writing in an evocative analytical way. This research therefore has been fundamentally a writing activity. Van Manen (1990) describes writing as method. Writing and rewriting also orientates us away from the contextual particulars towards a more universal sphere. By placing us at a distance from the lived experience, writing allows us to separate it from a context that may have overshadowed it. Writing involves distancing ourselves from confrontation with what we know. It abstracts our experience of the world, yet it also makes concrete our understanding of the world.

Van Manen (1998) suggests five linguistic techniques that assist the researcher to concentrate on what the written text says and the conceptual aspect of achieving this - lived throughness, evocation, intensification, tone and epiphany. Lived throughness requires the phenomenon to be illuminated through concrete description. Concrete examples of an experience assist the reader to recognise the experience. Research that involves interviews, such as this research, uses the participant’s words in order to provide this sense of lived throughness. Evocation is concerned with providing the reader with a vivid image in order that they can reflect on it. Intensification means words are given “their full value” (van Manen, 1998, p. 355). This is done using various techniques that appeal to the senses of the reader such as the use of rhyme, rhythm, and repetition. The tone aims to reach the feelings of the reader.

5-Maintaining a strong and orientated relation

In order to complete hermeneutic phenomenological research, van Manen (1990) suggests that the researcher must make explicit their orientation to the research. My orientation is as a palliative care nurse and as a nurse researcher aiming to develop a deeper understanding of the essence of need and service provision at the end of life. In my role as researcher, I continually returned to the orientation and to the participant’s lifeworld in order to avoid abstract theorising and in doing so, change the intended focus of the research. Hermeneutic phenomenology is intended as an action stimulation exercise; therefore, the content and expression of the research must be consistent with the paradigm of the researcher’s orientation.

6-Balancing the research context

Researchers are encouraged by van Manen (1990) to constantly hold the meaning found within the whole against the meaning found in the parts. The interpretative process is therefore circular, weaving back and forth between the part and the whole. Van Manen (1990) encourages researchers to go beyond existing, available interpretations found in the literature, and commonly held beliefs, to follow a more authentic and deeper analysis. This demands an enduring commitment on the part of the researcher to stay true to the text and to honour the lived experience of the research participants.

Van Manen (1990) suggests several ways of textually organising the writing of a phenomenological research project. These include thematical, analytical, exemplificative, exegetical or existential organisation. He advises that the way the writing is textually structured must suit the research content and design.

Critique of hermeneutic phenomenology in nursing research

The nursing literature contains considerable debate regarding the most appropriate research methodologies to inform nursing research (Allen, Benner & Diekelmann, 1986; Ford-Gilboe, Campbell, & Berman, 1995; Taylor, 1993). Early discussion concentrated on criticism of the positivist or quantitative approach to nursing research. Nurse researchers argued that the positivist approach ignores the complex and diverse context of human experiences and provides knowledge that is not always directly applicable to nursing practice (Omery, 1983; Taylor, 1993). The positivists' response was to dismiss the applicability of qualitative research informing nursing practice on the grounds that it is overly subjective, undisciplined, not generalisable, ambiguous and lacking in rigour (Guba & Lincoln, 1995; van Manen, 1990). This controversy continues but it is now commonly agreed that different research questions require a variety of different paradigmatic approaches and that no one single approach is necessarily superior to others, they can be complementary (Allen et al., 1986; Dzurec, 1989; Taylor, 1993). Sieber (1973) suggested combining case studies with surveys which integrated both quantitative and qualitative research, which lead to the emergence of mixed methods movements throughout the 1970 and 80s. Researchers in social and behavioural sciences were advocating for combining quantitative and qualitative approaches to the study of various social phenomena (Creswell & Plano Clark, 2007; Onwuegbuzie & Daniel, 2006; Tashakkori & Teddlie, 1998, 2003a, 2003b). The combining of both approaches is now most commonly known as mixed methods research, which mixes or combines quantitative and qualitative research techniques into a single study. Johnson and Onwuegbuzie (2004) state philosophically, it is the ‘‘third wave’’ or a third research movement, a movement that moves past the recent paradigm wars by offering a logical and practical alternative (p. 17).

Numerous philosophers have embraced phenomenology since its inception in the 1800s, resulting in a number of different interpretations. Spiegelberg (as cited in Cohen, 1987) referred to this continuous philosophical evolution of interpretations as the ‘phenomenological movement’. As a result of this ‘phenomenological movement,’ nurse researchers using phenomenology as a methodology are confronted by an array of choices in theoretical underpinnings. Walters (1995) accuses nurse researchers of often writing as if there is one single phenomenological method. Koch (1995) agrees with this sentiment, observing that nurse researchers often explicate the procedures and techniques undertaken but omit details regarding the actual philosophical underpinnings of the research. Walters and Koch suggest that nurse researchers should explicate the theoretical origins and philosophical underpinnings of their chosen methodology. These authors suggest that typically, phenomenological research methodology is either influenced by Heidegger or Husserl and, if the researcher is not clear about which philosopher’s teachings underpin their work, inconsistencies result, which jeopardise the integrity and rigour of the research.

Crotty (1996) has also critiqued the use of phenomenology in nursing research. Crotty refers to two types of phenomenology. Firstly, ‘mainstream phenomenology’, which he suggests, is authentic and is influenced by European philosophy. And secondly, ‘new phenomenology’ developed on North American principles, which he suggests relies on psychological beliefs and lacks the inclusion of phenomenological principles originating from the European origins. Crotty suggests that nurse researchers have relied on the stepwise methods of phenomenologists such as van Kaam and Giorgi, which he believes distort the true method of phenomenology. Crotty suggests that much of what nurse researchers’ term ‘phenomenological research’ is, in fact, not and that this should be acknowledged. In addition, Crotty criticises nurse researchers who rely on this ‘new phenomenology’ as being ‘excessively subjective’ or attempting to describe people’s personal experiences rather than explicating “what people experience”, which he suggests is the aim of authentic/ mainstream phenomenology (Crotty, 1996, p. 3). In the following section some of these criticisms will be addressed.

The methodology chosen to guide this research was a combination of the original works of the European phenomenologist Martin Heidegger and the contemporary interpretations of Max van Manen. This approach resonated with my interest in understanding how palliative care nurses experience their practice world.

Trustworthiness and Rigour

Historically qualitative research has been criticised for its perceived lack of scientific rigour. Suggested factors include the influence the researcher may have on participants, especially if an unstructured interview occurred, and the method by which the data are selectively described, reported and interpreted. Sandelowski (1997) suggests that many qualitative researchers still measure their work by quantitative measures of rigour: "…validity, reliability, and generalisation" (p. 127). She also suggests that repeatability is not fundamental, and proposed that the creativity of the research should not be lost in pursuit of rigour.

In response to the criticism of the possible interpretative approach to phenomenology, Lincoln and Guba (1985) developed a set of criteria specifically designed to assess trustworthiness of qualitative studies, which include credibility, transferability, dependability and confirmability. Sandelowski (1986, 1994, 1997), Koch (1994, 1996) and Koch and Harrington (1998) have been largely influential in bringing these criteria into the nursing research domain. Van Manen (1990) suggests trustworthiness in phenomenological research is achieved through orientated, strong, rich and deep phenomenological writing. Ray (1994) describes the credibility of phenomenological methodology "…as the 'phenomenological nod' – where the description and interpretation of experiences are something we can nod to and recognize as experiences that we had or could have had" (p. 131). Polkinghorne (1988, as cited in Bailey, 1996, p. 188) calls it verisimilitude: "…results that have the appearance of truth or reality" and are "…well-grounded and supportable". Guidon (as cited in Plager, 1994, p. 77) believes: "…truth is envisaged as the emergence of a clearing or opening that releases entities from hiddenness … The description is measured not by criteria of correctness, but by criteria pertaining to its consequences for our lives." Bailey (1996), in speaking of Polkinghorne's (1988) notion of verisimilitude states: "…reliability refers not to the reproducibility of a similar story on a subsequent occasion but to the dependability of a one-time narrative database" (p. 189). This highlights qualitative research outputs which should be; “…meaningful or important” (Bailey; 1996, p. 189) or whereby knowledge is able to cause: “…changes in the way people and events are configured or thought about…knowledge is ‘used’ when it informs and even emancipates thought and when it permits sense to be made of previously incoherent and nonsensical events” (Sandelowski; 1997, p. 26).

The criteria for meeting and applying methodological rigor, and van Manen’s recommended approach to phenomenological writing are outlined below:

Credibility – this is the process of ensuring the results are consistent with the information gathered from the original source (Sandelowski, 1986). By ensuring the participants received a copy of their transcripts they were able to check for authenticity, ensuring that accurate information was being used. I have used direct quotes from these transcripts to illustrate participant’s experiences (Sandelowski, 1986, 1994).

Fittingness – this refers to the ability to apply the findings to another context. I used selective sampling for this study, and therefore I am not suggesting the results be generalised to other groups, as the very nature of hermeneutic phenomenology refutes the possibility that two people will experience a situation in the same way. In describing the experiences of the participants, I aimed for the reader to be able to build knowledge and understanding of the components of the experiences that were shared.

Dependability – this requires the researcher to clearly describe the research process and decisions made along the way. By describing the design of the thesis, research process and framework used for the analysis, I intended that the reader will independently have the opportunity to decide about the reliability of the research.

Confirmability – this is achieved when the above three points (credibility, fittingness and dependability) are met. My supervisors reviewed the research process as it unfolded in order to assess the accuracy of the document.

Van Manen (1990) suggests attentive phenomenological writing can ensure methodological rigour. He suggests text needs to be orientated, strong, rich and deep.

Orientated – this refers to the orientation of the theory, that which holds an awareness of the relationship between content and form, text and textuality, speaking and acting (p. 151). The text is focused on the phenomenon of concern and the discipline of the researcher. Therefore, throughout this research I maintained my orientation as a researcher and a nurse.

Strength – the need for the research to strengthen practice and to capitalise on the orientation of the researcher. Research impacts on our understandings and interpretations and subsequent ways we deal with people. Therefore, I have endeavoured to maintain my nursing focus in this research by looking at the implications of the participants' experiences on palliative care nursing in particular, but this research will have implications for all health practitioners in palliative care.

Rich – the text explores a phenomenon in all its "experiential ramifications" (p. 152). Phenomenological research will be evaluated positively if it evokes a resonance between the description, interpretation and the reader's experience and/or understanding; if it causes the reader to see "that which shines through, that which tends to hide itself" (p. 130). I illustrated this through full descriptions of the participants, experiences.

Depth – this refers to descriptions that explore the meaning of the phenomenon beyond what is immediately experienced. I have endeavoured to interpret the participants' experience in a way that reveals the essence of the phenomenon.

Field Journal

It has been recommended in qualitative research that a reflective journal be kept as an additional way of ensuring rigour (Koch, 1994, 1996; Koch & Harrington, 1998; Sandelowski, 1986). The reflective journals that I kept, resulted in me having a deepened self-awareness to remaining open to the participants' experiences described at the interview. It enabled my pre-understandings to be explored in order to understand the way in which one may influence the interpretation of the narrative. It also enabled a recording of the context of the interview, and observations that could not be captured on the audiotape. For example:

> …a priceless gift offered to me today as I reflect on being invited into the bedroom to observe the lifecycle of change. The physically frail, elderly body of mother, young physically fresh but equally vulnerable body of baby and the in-betweeness of daughter. Vulnerable and fragile in her own right as she grapples with loving and losing. I could feel her struggle with words to try and explain the unexplainable as we explore care at the end of life. Baby softly snuffling in the arms of a grandmother she was not to know, a grandmother finding peace as her hand fondles a crucifix. She had become restless her daughter explains, and they (the medical team) were at a loss to know why and her dying mind no longer capable of articulating why. She had been brought up attending church on Sundays but this ritual was now limited to Christmas and Easter, sedation via the syringe driver had been mentioned to relieve this distress but the daughter by chance handed her the crucifix necklace she once wore, this caressing and following the familiar shape with her bony fingers had settled her agitation for the previous 48 hours, no need for medication. I sense the warmth in the room as the rays of the late afternoon sun filter through the row of pines trees, I experience the warmth portrayed between 3 generations and feel invited to reflect on birthing and dying, loving and grieving, a profound moment… the moment of coming together - a joining together of the life cycle.…the long but comfortable silences and shared understanding and the privilege to be fully present in the moment with another, a transpersonal caring moment . . . . (personal reflexive journal).

My journal entries also allowed me to explore my writing, to develop the technique of intentionally drawing the reader into the text, almost as if entering into dialogue with it. Placing myself at a distance from the lived experience, writing allowed me to separate it from a context that may have overshadowed it. Exploring the notion of being abstracted from my experience of the world, yet also making concrete my understanding of the world. As my engagement with the research process deepened, the field journal became a reflexive journal adding credibility and rigour to the methodology. I shared some of my journal writing with a colleague whom I regard as a highly skilled palliative care practitioner, and whose opinions I value greatly, to see if the reflections of living with these experiences resonated with her experiences in practice, and whether the essence of them were revealed in a meaningful way. This relationship was that of a critical friend, prepared to challenge, and ask questions that allowed me to find other possibilities and insights supporting me to be as Taylor (2006) suggests, the ‘sense maker’ of my own reflections (p. 60). I incorporated her critique by writing more succinctly at a deeper level.

In summary the field journals provided a personal account of my thinking and processing through the research journey and together with the transcripts, contributed data to be analysed for the research project.

Human Science Approach and Nursing

In this research my intention was to seek the lived experience of palliative care practice from a range of colleagues involved in the field but as a nurse, and with nursing colleagues making up the largest number of palliative care practitioners, I view this work through a nursing lens. Nursing focuses on individual, therapeutic caring relationships. If therapeutic caring relationships are absent then it is arguably not nursing at all. As Peplau (1952) suggested, nursing is defined in terms of relationships between a nurse and his/her patients, and Kirby (1995) later added that the practice of nursing is carried out within relationships, it is in essence a special form of relating. McKee (1991) suggested that, rather than asking the nurse ‘what did you do?’ in a nurse–patient relationship, a more appropriate question might be ‘what happened between you?’ If nursing is viewed in this way, it becomes not *one* of the caring sciences, but as *the* science of caring, it is the science of caring *for* by caring *about*. This is fits with a hermeneutic human science concept although it has taken nursing some years to connect with a human science approach as its earlier research and teaching stemmed from a social science background. When nursing began to emerge with its own knowledge base, the early nurse academics had degrees in anthropology and sociology and a social science framework was dominant. Rolfe (2015) questions why the ‘science of society’ was ever considered relevant to nursing when he argues nursing should *not* be concerned with the social, *not* with what it means to be a member of a social group, but *with* the human, *with* what it means to be a person (p. 146). He does not suggest that nurses should not take into account the social forces and political impact on what they do, but highlights that the practice of nursing is at the point of contact, an interaction between unique and singular individuals.

The hermeneutics of caring, grounded in a human science paradigm could support continuing development in nursing practice and the patient experience through the authentic *I-thou* relationship (Buber, 1937). Hermeneutics allows us to come to a shared understanding through dialogue, discourse and reason. Coming to an understanding in a nursing situation involves thinking, theorising, researching and doing, in partnership with the person in our care. It allows us to attune to their needs, wants, dreams, and their unique place in the world. Together we make sound practical, aesthetic and ethical decisions about their care.

Jean Watson and Human Caring Science

Jean Watson's caring science has been influential in my practice and it is fitting to consider caring science as a philosophical underpinning to the methodology for this research. Watson is one of the few nursing theorists who considers not only the cared for, but the caregiver, which is relevant to this research. Upholding her caring theory allows nurses to practise the art of caring to provide compassionate and respectful ease of pain and suffering, to promote healing and dignity and in so doing, contributes to our own health, through finding meaning in our work.

The main concepts of Watson's theory are 'carative factors', transpersonal caring relationships and the occasion/caring moment (Watson, 2001). The carative factors developed in1979 and revised in 1985, were viewed as the core of nursing. Carative was used to contrast to curative factors used in conventional medicine. This was to "honour the human dimension of nursing's work and the inner life world and subjective experiences of the people we serve" (Watson, 1979, p.50). They carative factors comprised 10 elements:

1. Humanistic-altruistic system of value
2. Faith-Hope
3. Sensitivity to self and others
4. Helping-trusting, human care relationship
5. Expressing positive and negative feelings
6. Creative problem-solving caring process
7. Transpersonal teaching-learning

8. Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces. (Watson, 1979, p. 75)

Watson continued to refine her theory and introduced clinical caritas processes which have since replaced the carative factors, as she expanded on the spiritual dimension of personhood. She explains the word *caritas,* originating from the Greek vocabulary, meaning ‘to cherish and give special loving attention’. The following are Watson’s (2001) carative factors translated into the clinical caritas processes:

1. Practice of loving kindness and equanimity within a context of caring consciousness
2. Being authentically present, and enabling and sustaining the deep belief system and subjective life world of self and the one-being-cared-for
3. Cultivation of one’s own spiritual practices and transpersonal self, going beyond ego self, opening to others with sensitivity and compassion
4. Developing and sustaining a helping-trusting, authentic caring relationship
5. Being present to, and supportive of, the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared-for
6. Creative use of self and all ways of knowing as part of the caring process; to engage in artistry of caring-healing practices
7. Engaging in genuine teaching-learning experience that attends to unity of being and meaning, attempting to stay within others’ frames of reference
8. Creating healing environment at all levels (physical as well as non-physical), subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated
9. Assisting with basic needs, with an intentional caring consciousness, administering “human care essentials,” which potentiate alignment of mind-body-spirit, wholeness, and unity of being in all aspects of care; tending to both the embodied spirit and evolving spiritual emergence
10. Opening and attending to spiritual-mysterious and existential dimensions of one’s own life-death; soul care for self and the one-being-cared-for. (Watson, 2001, p. 347)

These factors/processes were in the forefront of my awareness in my role as a researcher engaging in the relationship with those being interviewed. They formed part of the method of undertaking the research, as I created a supportive and comfortable environment to engage in the interviews, to being authentically present, being compassionate, supportive and sensitive to participants’ situation to learn from, and engage with the lived experience and to share if, and when appropriate, knowledge and experience that may be of benefit in the relationship.

Caring Ontology within Research

Hills and Watson (2011) stated the importance of an ontology of caring:

> Caring Science provides this deep underpinning for a scientific-philosophical-moral context from which to explore, describe, and research human caring-healing phenomena as integral to our humanity, as the disciplinary foundation for nursing. Caring Science clarifies for the profession and the professional, the question of ontology, that is, what is our worldview of reality? What is the nature of Being and Becoming and Becoming human in relation to the larger infinite universal field of life itself? (p. 13).

If caring is the core of nursing, then it should permeate nursing research. Cara, O'Reilly and Brousseau (2017) suggests that underscoring an otology of caring for nursing research, the research becomes a relational human process. The researcher must "be with" the participants while sharing their meaning and experience regarding the phenomena being studied, honouring their voice and remaining "true" to their perceptions, beliefs and meanings pertaining to their lived experience. In a relational caring process, the researcher and the participant contribute to the phenomena being studied. Watson (2012) explains that a caring moment corresponds to a sacred space where two people can connect, exchange their ideas and experiences and come to a shared understanding or decision. Research that is informed by human caring ontology leads the researcher to create a research caring moment which contributes to each person's transformation of personal growth, insights and consciousness, as well as expanding knowledge in nursing in regard to the phenomena being studied, in this case, the palliative care lived experience.

Encouraging participants to share their experiences and for their voices to be heard, (caritas process number eight - creating healing environment and caritas process number five - the expression of positive and negative feelings – authentically listening to another's story, Watson (2001)) invites the researcher to provide an environment that is filled with openness, trust and support, which encourages sharing. Watson also offers compassion for consideration, "listening with compassion and an open heart, without interrupting" (Watson, 2003, p. 201) being essential to grasp the person's story.

Ray (1991) also refers to the importance of being present in her phenomenological method of caring inquiry, and Watson (2012) connects with Husserl's phenomenological reduction as being concerned with the notion of presence, as she explains:

> Husserl's ideal of phenomenology involved a different attitude: it involved placing within brackets the existential historical aspects of experience and concentrating on the essence or the ideal types exemplified by the experiences that we either have or are able to conceive of ourselves as having. Phenomenology studies such essences and clarifies the various relationships between them . . ., Human phenomena (such as caring, caring moments . . .) are not object-like, they cannot be inspected or studied in the manner of objects. They have to do with the "how" rather than the "what". (Watson, 2012, p. 95)

Ultimately, the researcher's presence assists authenticity, for respectful engagement with participants' stories. This does also mean that the researcher is affected by the story. According to Buber (1970), both persons must experience mutuality of presence within the I-Thou relationship, in order for a genuine dialogue to take place.

A relational, caring, ontology invites the researcher to understand the phenomenon with openness, consciousness and humanness. The co-created stories become richer, reflecting the participant's reality while revealing the essences of the phenomenon and thus contributing to new epistemology.

Phenomenological Writing

Writing and rewriting were an integral part of the interpretive process that I tussled with over time. Rather than being the final act in the research process, writing is an essential way of giving appearance and body to thinking (van Manen, 1990). It facilitates the reflective activity that a hermeneutic interpretation requires. As I have historically struggled with my writing, I was often frustrated, confused and doubted my ability to see beyond the darkness of blind alleys I came upon. Also, aware that rushing interpretation risks premature closure (Ray, 1994), I spent time 'intuitively dwelling' with the data and 'letting the interpretation be' and 'savouring the sacredness of the stories told' when facing what I thought was an impasse. On reflection, I believe these moments of impasse were times which enabled me to gain insight through engagement of reflection and reflexivity.

In an effort to stay close to the phenomenon, I have tried to 'show' rather than 'tell' when presenting this work. I sought to share a sense of living the experience through arousing feelings, stirring memories and stimulating further questions, so that we may continue to learn and reflect our way forward to improving our human-to-human connectedness with those who are dying. I had the opportunity in 2014 to attend the qualitative research conference in Newcastle, Australia, and a pre-conference workshop facilitated by van Manen to explore phenomenological writing. We were invited to develop a reflective relationship with language which disturbs it's 'taken-for-grantedness'. I was to experience the idea of writing being similar to reading, where one can become lost in the text, I entered into another space, a solitary and self-forgetful submission in textual reality. Insight can occur in this space but also linguistic darkness, of producing words but not writing. Van Manen also explained that something peculiar may happen when phenomenological text is read aloud. When giving a conference paper using phenomenological writing, the audience responds with silence, not because they have nothing to say, but because they have been drawn into the text, struck with the perplexity, the silence, the wonder. He suggests when the text is successful and the reader or listener is open to it, the effect is almost inexplicable, of being struck with wonder. This lived experience occurred for me at this conference when giving a paper on one small aspect of this research. I was faced with silence at the end of my presentation, an uncomfortable moment of concern that I had not presented what people were looking for, self-doubt almost overwhelmed me and I felt the comfort of relief that I had presented to an international audience that I need never see again. I was to receive the best paper award at the conference, which was a humbling surprise, and a lesson to trust in the development of phenomenological writing.

In this chapter I have outlined the philosophical and theoretical influences that have guided me in creating the design for this research. It is a philosophical approach, primarily concerned with how human beings interact with the world around them. It describes a relational ontological position with a participative epistemology supporting a deep understanding through the exploration of the lived experience. I have demonstrated the extent of my understanding of these philosophical principles, and how I used these principles as a framework and moulded them to suit the phenomena being explored. The following chapter will describe this process further and detail the research process at it unfolded.

Chapter 4 Method

"Never lose an opportunity of urging a practical beginning, however small, for it is wonderful how often in such matters the mustard-seed germinates and roots itself."- Florence Nightingale

Chapter 3 outlined phenomenology as the methodology for this research. The first part of this chapter outlines the research design as it was intended at the outset. This discussion includes details of ethical considerations and outlines the procedure for gaining ethical consent from the University of Canterbury's Human Ethics Committee. The second part of this chapter will address the realities of the method.

Aim

This study using hermeneutic phenomenology informed by van Manen, aimed to explore, describe and conceptualise the experience of the health professionals involved in palliative care delivery and explore and describe the experiences, thoughts and ideas of the person and or family who are consumers of the service by:

1. Describing, identifying and portraying the personal experiences of those who give and receive care at the end of life
2. Seeking to determine whether the experiences and perceptions of delivering palliative care according to the World Health Organisation and Ministry of Health philosophy of care within the community
3. Exploring opportunities to fulfil any unmet community need for end of life care
4. Awakening a shift of consciousness that creates new realities and creative opportunities to unfold for the provision of palliative care in the future
5. Expanding current understanding of reciprocity in relationships between health professionals delivering palliative care and patients receiving it.

Interviewing health care professionals delivering palliative care services and the patients and families receiving care, enables an opportunity to collect information about service delivery and the philosophy that underpins that care, as a way of determining the future direction that meets the growing needs of our society.

Participants

I began in consultation with Hospice New Zealand, (the national umbrella organisation for Hospices in New Zealand) as they were also interested in the answers from this research and offered assistance in disseminating the information about the study to their membership should I require it. They selected five services they thought would give a good spread of opinions, as they ranged from smaller regional services to larger more comprehensive hospice programmes. Distancing myself from making the selection of services to be invited to contribute, allowed for greater objectivity. Hospice NZ was also given all the information about the research project, so that if a query was raised regarding the study, they were fully informed. These services were complemented by two hospital palliative care services, and three rural and two urban general practices. Courtesy letters were sent to service managers (see Appendix A) inviting participation, and all services agreed. A cover letter was then sent to the health professionals in each service (see Appendix B) with an information sheet (see Appendix C) and consent form (see Appendix D).

I had to be mindful of ensuring freedom from coercion, as I was known to many of the potential health professional participants and service providers. The field of palliative care is small in New Zealand, and as a result of my years in practice both at local and national levels, it would be reasonable to suggest that I would be known to a greater or lesser extent to potential health professional participants, despite using a convenience sampling selection process. I was asking them to share with me their thoughts, perceptions, and experiences in practice and how we might meet the growing demands on services. Some may also have been, or were considering being, a student in the post graduate papers I facilitate. Therefore, I reflected on how I would feel, sharing with a researcher my ideas when there may be a perceived power imbalance between lecturer and student, or a conflict of opinion. Reflecting also, on how my involvement may be seen through the service provider lens, I chose not to indicate that this research was being undertaken for a PhD. Over my years of involvement in the industry I have undertaken work/roles for many services in a variety of capacities such as interviewing for staff, auditing, managing services between leadership appointments, staff appraisals, assisting with policy and documentation, supervision, providing education to name a few. There have been times when services have offered to support me in return for this work, if there was ever a need. I did not want them to feel any sense of obligation to support this research to assist me personally, and indicating it was to be part of a PhD may have invited this response. I wished them to participate because they were interested in the topic and were free from any potential coercion. I discussed this stance with the Human Ethics Committee, who supported my rationale for non-disclosure. Ethical consent was granted (HEC2013/122) see Appendix E and F.

I have been in the position of being interviewed for nursing and allied health research and sharing what I had predominantly held as personal information, with interviewers. In those situations, I was very keen to support the research, I developed a rapport with the researchers, felt a great deal of trust and respect for them as they were also well known in their fields, and I looked forward to learning from their findings. It was important to me to build that same rapport, trust and respect for those gracious enough to give their time to this research. If this relationship was supportive and professional, the health professional participants were more likely to offer the opportunity to the consumers of their respective services to also participate in the study. It was important to seek input from both palliative care providers and consumers to ensure synergy or identify gaps in understanding, to support a beneficial future for all.

Researcher rapport is needed when conducting research with individuals. Pitts and Miller-Day (2007) identify rapport as the key focus at the beginning of research, identifying five phases of development (other orientation, self-in-relation to other, self and other linking, interpersonal connection and partnership) that turn a moment of connection into a relationship. Attentive listening to the stories of the research participants is important for establishing mutual trust. As such, listening includes a strategic element, which is acknowledged as part of qualitative research interviews. However, being guided by respect and ethically sound reasoning, as well as constantly operating through an open receptive attitude, contradicts the notion of attentive listening as “a fake.” It would be impossible to gain mutual trust and rich descriptions if the researcher is not genuinely interested in the experiences of the researched. According to phenomenological methodology, a genuine interest coupled with an attitude of openness and wonder that puts pre-understandings at risk, is essential in order to explore lived experience in any depth (Dahlberg, Dahlberg, & Nystrom, 2008, van Manen, 1997).

Data collection occurred through semi-structured interviews, beginning with the health care professionals. The interview guide (See Appendix G) consisted of a generalised statement and an open-ended question: “As you know, I am interested in finding out about your experience of the effectiveness of the philosophy of palliative care and its clinical application in your community, may I invite you to share your thoughts/experience/stories of practice in this field?” and for the consumers of the service: “I am interested in finding out about your experience of the hospice (or palliative care) service and its philosophy of care, may I invite you to share your thoughts/experiences of this service?”. These invitations were designed to act as a catalyst to encourage and enable the participants to talk, with no imposed limitations of time, and to allow the researcher to listen, and to be fully present in the moment of their sharing. Further questions were used as a prompt only, or to seek clarification, depending on how the participant proceeded, but it was my intention to keep these to a minimum and a focus on clarification of the story. Using a semi-structured interview as the method, was consistent with the methodology underpinning the study in that it was, “…used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon” (van Manen; 1990, p. 66).

A letter to potential consumers of the services, information sheets and consent forms were distributed after health professionals identified potentially interested people. (see Appendix H,I and J).

Interviews were offered as one-on-one or as a family group for the consumers, and one-on-one or focus group for the health professionals. Participants could determine their preference. Interviews were recorded using a tape recorder, and transcribed by a transcriber who signed a confidentiality agreement (see Appendix K). The participants were to receive a copy of their interview transcript for their own interest, and to validate the accuracy of the transcription. They would have the opportunity to amend the transcript if it did not reflect their memory of the interview. This process was to ensure that their views were not misrepresented, and their consent to use the data would validate the content. The venue for the interviews was determined by mutual agreement, where participants felt relaxed and in the right space to talk. This ranged from a room in a hospice or hospital facility, to private homes of families and quiet cafés.

Ethical considerations

Approval for this study was obtained from Canterbury University's Human Ethics Committee (Appendix E and F).

A courtesy letter was sent to the Manager of key provider services in the region (see appendix A) inviting participation from their staff and patient/families, ensuring confidentially regarding the participants and the service location. Information sheets and a letter of invitation to participate, as mentioned above, were distributed by the service to the health professionals with instructions to contact the researcher with any queries, or informing the researcher of their interest in taking part.

The information sheet gave contact details of the research supervisors and the ethics committee, should they wish to discuss any concerns. I was available to meet with each participant in person, to discuss any questions they might have before signing the consent form. The consent form stated that their participation was voluntary and that they could withdraw from the study at any time up until the analysis of the data took place, and that their data would be returned to them or destroyed if they were to withdraw. There was an explanation that all information would be confidential and held in a secure manner. They had the right to use their own name in the research or to choose a pseudonym.

Health professionals were able to identify consumers of the service and offer the information and consent forms to them for their consideration to take part. The same ethical considerations were granted to them, with the additional respect for energy levels, given they were people living with a life-challenging illness or people who had been recently bereaved and were coming to terms with the loss of a loved one. Participants had the right to be protected from discomfort and harm while maximising the potential benefits of participating in the study (Burns & Grove, 1993). It was made known to the participants that they may feel overwhelmed or experience emotional discomfort while recounting experiences or scenarios relating to their care or service provision. If this occurred the researcher would allow time to work through this and provide the necessary support, before continuing the interview. If the distress was severe, the participants would be asked if they wished to continue the interview at another time or to withdraw completely, and whether they required any other support. Trained counsellors and/or family support workers were available within the services should additional support be required, at no cost to participants. It was stressed that participants may withdraw from the study up until the data analysis took place with no consequences for themselves or the research. I checked that participants understood this before they were interviewed, at the beginning and end of the interview, and again when they had read their transcriptions and had time to reflect.

I made a strong commitment to equalising potential power relationships during the interviews. This was done by encouraging openness, and by developing rapport and trust, especially during the times participants were verbalising sensitive and private feelings.

Research at the end of life is diverse in methods, approaches, and goals, and focuses on a time that is personal and precious. Proximity to death strikes us as an inherently vulnerable time, but how do we compare it with the experiences of other population groups who are facing life challenging diagnoses or injury? Indeed, the vulnerabilities of many at the end of life are profound, and are a substantive reason to be concerned about research with these populations. However, recognizing the impact of health crises and medical events on the lives of potential research subjects is something that needs to be applied across all research with human subjects, not just with those in the various trajectories associated with the end of life (Phipps, 2002).

Duke and Bennett (2010) undertook a critical review of the literature related to the ethics of palliative care research and provided a framework for consideration, raising the following questions to reflect upon:

Is the research morally appropriate?
Are research participants likely to be vulnerable?
Are researchers likely to be exposed to risk/harm?

Are non-research staff likely to be exposed to exploitation?
Is gatekeeping a potential concern?
Is the research as inclusive as possible?

Is the research morally appropriate?

In order for the research to be considered morally appropriate, the aim of the research must be to address an issue about which little is known or there is contradictory opinion, or the aim is to unveil new knowledge. For this research I was aiming to highlight new knowledge and/or identify service gaps to highlight the future direction for palliative care in New Zealand. In gaining this new knowledge, the risk to participants must be balanced with the benefits of participating. Minimal risk is considered to be that which does not expose people to harm or discomfort greater than that which they would encounter in everyday life or during an episode of care (Karlawish, 2003). Seeking the lived experience of service providers and consumers in and on practice, would not expose people to any additional risk than they would encounter in day to day care/caring.

Are research participants likely to be vulnerable?

Duke and Bennett (2010) note there has been substantial debate in the literature about the vulnerable nature of the study population for palliative care research, yet there is little evidence to support this stance. Certainly, if potential participants are close to death, the precious time left might be better spent with loved ones, but it would be regrettable to assume or label all people at the end of life as vulnerable, as this devalues their personhood and prevents them acting upon their beliefs and altruistic motives (Mount, Cohen, MacDonald, Bruera, & Dudgeon, 1995). Evidence suggests people value the opportunity to participate in research, knowing that what they contribute to the research findings may not benefit themselves, but have the potential to benefit others (Bellamy, 2011). From a personal experience of this, I was involved in a study (Fairhall et al., 2011) that explored hospice patients' views about participating in research, which required regular blood sampling and despite this additional procedure, their participant experience was positive for largely altruistic reasons.

Gysels, Shipman, and Higginson (2008) invite us to consider that if palliative care is about helping people to live fully until the very end of life then they should be allowed to participate in research that has the possibility of helping others and potentially themselves. Indeed, many people receiving palliative care are still living active and full lives and would not consider themselves to be vulnerable. Classifying them as such therefore challenges their autonomous decision making. All participants of research should be treated as autonomous decision makers (Judkins-Cohn, Kielwasser-Withrow, Owen, & Ward, 2014). Respecting a patient's autonomy is an important component of ethical research. Perry and Fine (2003) suggest excluding palliative care patients from research is unethical by removing their autonomous choice and decision making. Participants have a right to refuse to be involved in the research and can choose to withdraw at any time and without explanation. This process was highlighted in the information sheets and reiterated in the consenting process. Informed consent is underpinned by the ethical principles of autonomy and beneficence (Judkins-Cohn et al., 2014).

Are researchers likely to be exposed to risk/harm?

Sivell et al., (2015) caution that palliative care researchers are at risk from being repeatedly exposed to the distress and suffering associated with people who are nearing the end of their life. Furthermore, analysing interview data and repeatedly listening to distressing stories during the transcribing process can become an emotional burden, reminding the researcher of their own mortality or indeed bringing up their own previous experiences of death and dying (Clark, Ingleton & Seymour 2000). Whilst reflecting on the above writings of Sivell, Clark and colleagues, I believe this exposure to risk/harm as researchers was more likely to be a reality for beginning researchers or those less experienced in palliative care practice. As my career has been situated in the field of palliative care for many years, my personal knowing, insights and reflective practice have been tools that sustain my practice, and I knew where and how to seek additional support should I need it. I was aware in the role of researcher in this work, that moral distress may be highlighted. The concept of moral distress first formulated by Jameton (1984) came out of the nursing literature at a time of rapidly expanding medical technologies and a patient's rights movement. The complexity of decision making had markedly increased, giving rise to treatment plans being constructed that deliverers of them felt fundamentally opposed to. To believe one knows what the right thing to do is, and not being able to do it can be disempowering and demoralising. Self-awareness and being comfortable “sitting with suffering” can be helpful in ameliorating moral discomfort (Rattner & Berzoff, 2016). Ethical competence is also crucial as it empowers clinicians to thoughtfully analyse dilemmas and constructively work through them (Rushton 2017). Ruston (2017) suggests that nurturing such skills helps develop “moral resilience” which refers to the capacity of an individual to sustain or restore their integrity in response to moral complexities, confusion, distress or setbacks. Potential exposure to moral distress in this research may have come from listening to participants’ stories then leaving the interviewer with no role to follow up or provide ongoing support. I was able to refer the consumer group back to their health care providers, and for the health care professionals I could refer them to ongoing support. A sense of “unfinished business” and a continued concern for the wellbeing of participants after interviewing has been highlighted as a concern for the researcher-clinician (Hay-Smith, Brown, Anderson, & Treharne, 2016).

I utilised the skills of a transcriber for the majority of transcripts, a woman of utmost integrity and skill in her field of work. I was mindful of a previous experience of using the skills of a transcriber who identified with the situation she was transcribing, the experience of a mother and a dying child, the transcriber herself a mother with a daughter the same age. Whilst it was not traumatic in a negative sense, she felt connected to this woman whom she had never met, her heart went out to her. I made time to listen and always checked in to see if any stories had raised issues for her. I had learnt a poignant lesson during this experience, and reflected on my naivety in not considering the need to offer more support to the transcriber at the outset. I have ensured I take the time in subsequent projects, and have encouraged this practice with colleagues and students undertaking research on sensitive topics. The transcriber for this work demonstrated her professionalism and resilience, based on many years of working with health researchers. There were no identified issues raised for this research.

Are non-research staff likely to be exposed to exploitation?

During this research I was asking staff of the respective services to identify potential consumer participants in addition to their already busy workload. Duke and Bennett

(2010) note a lack of discussion in the literature on ethics related to the dignity, rights, safety and well-being of non-research staff (p.118). They refer to Daniels and Exley (2001) who describe how nurses had significant responsibility for giving information, obtaining consent and liaising with their colleagues yet felt they had no ownership in the study. Seymour et al. (2005) and Hopkinson, Wright and Corner (2005) also note the respect required when engaging a service and staff in recruitment of patients and their carers. My intention in interviewing the health care professionals before the consumers of their services was to develop rapport, respect, trust, and caring professional relationships that would invite enquiring minds to consider the way forward in palliative care service delivery, acknowledging that I was asking them to identify potential consumer participants and that this was adding to their workloads. I offered my gratitude for their contribution towards exploring this topic. I was also respectful if their intentions were supportive but pressure of time prevented their contribution.

Is gatekeeping a potential concern?

Gatekeeping by clinicians is a very real risk during the recruitment process, particularly for palliative care studies (Duke & Bennett, 2010). It is founded on the belief that potential participants need to be protected from any potential harm associated with being involved in research, and is a risk to inclusivity. Bond, Sutton, Glad and Siminoff (2003) and Witham, Beddow and Haigh (2013) suggest gatekeeping is particularly common in populations that are characterised as ‘vulnerable’ such as those who are living with mental illness or who are terminally ill. In the palliative care setting Hanson et al (2014) suggest 80% of studies struggle to recruit sufficient numbers. Kars et al. (2016) undertook a systematic review of gatekeeping in palliative care populations and found 1865 papers written since 2000. They identified five groups of gatekeepers, healthcare practitioners, research ethics committees, relatives, management, and other researchers. Their review was based upon literature that discussed gatekeeping as part of the investigations into attitudes and barriers to recruitment for research, and despite finding a significant amount of commentary, they suggested there is a need to conduct research into gatekeeping activity with patients at the centre of the research. Given gatekeepers may prevent access to relevant patients, this may present a significant challenge. Snowden and Young (2017) rose to this challenge by researching the common actions taken by nurses in the process of preventing patients from participating in palliative care research. They discovered a continuum of gatekeeping activities from nurses forgetting about the study (unconscious aspects) to actively disengaging from it (conscious aspects). They went on to develop a screening tool designed to ascertain the likelihood of these behaviours and attitudes which have impact on recruitment. By completing the screening tool, it brings gatekeeping out into the open at the very beginning of the research, to discuss underlying issues. Their findings are helpful as differing actions may help in mitigating the risks of gatekeeping.

Being aware that gatekeeping was a very real potential barrier to recruiting the consumer participants, developing rapport and trust at the outset of the health professional interviews was aimed at reducing this risk. As Snowden and Young (2017) identified, gatekeeping by nurses can create a substantial problem. However, the solutions are less clear (p.195) therefore developing the relationship would be important to help mitigate this risk.

Is the research as inclusive as possible?
In seeking the experiences and perceptions of delivering palliative care to our community, I aimed to interview a range of health care professionals across settings including hospital, hospice, age residential care facilities and community, in order to be as inclusive as possible of all disciplines and settings. Interviewing consumers of those services, including family members, would give well rounded perspectives.

I kept Duke and Bennett’s framework (2010) and their questions for ethical research in palliative care discussed above in the forefront of my mind as I engaged in this work.

Research Method – the Reality

Participants and Data Collection

The service providers who were sent courtesy letters, inviting participation from their staff and consumers all responded positively. They expressed interest in the topic and a convenient time was arranged to spend in their service, and their hospitality extended to making a room available for interviews. Most staff chose one on one interviews, and small groups within each service decided focus groups were more convenient for them.

Some suggested, as they had not been part of a research project before, they would be more comfortable being part of a focus group, to bounce ideas around. They all had stories to tell, and appeared to find it an enjoyable process and, in many cases a cathartic experience. The rich narratives gathered from the participants using the semi-structured interview technique ensured each participant was able to guide and explore their own direction within the question leading to a "…valid explication of the informant's perception of reality" (Minichiello, Aroni, Timewell, Alexander, 1995, p. 65). Inviting participants to share their experiences/stories of the effectiveness of the philosophy of palliative care and its clinical application in their community was an appropriate catalyst. It did not require further questions as a prompt because the stories flowed with apparent ease. This was true also for staff from the hospital palliative care teams and community general practices who participated in the research.

The majority of health professionals interested in participating were nurses, reflecting the reality of the workforce, but they were complemented by doctors, counsellors, family support workers, chaplains/spiritual workers, occupational therapists, a pharmacist, an art therapist and service managers. The differing professional lenses to view the philosophy through were refreshing, and invited a rich exchange of thought within the focus group interviews. All the participants from different health professional groups contributed significant moments in their practice, and indicated their willingness for these stories to be articulated through the research process to enable colleagues to learn and reflect on the impact of these moments of human-to-human connection when providing palliative care services. I have removed any patient or family names mentioned within these stories to protect their possible identification and privacy. I would ask you as the reader to read these moments of care in the spirit and context in which they have been given, and not attempt to discern the identity of any patients. The venue for the interviews ranged from a room in a hospice, hospital facility, private homes of families and quiet cafés, all mutually agreed on, and all offered an environment conducive for talking.

There were no changes made to the process of data collection as described earlier in this chapter for the health professionals. These participants entered the study with interest in the topic and a willingness to share their experiences. However, gate keeping was an issue that I found challenging despite the realities identified in the literature. All services had indicated they had consumer participants who would be interested, but upon my arrival to undertake the research in three regions, suddenly they had no one appropriate. I was reminded of a personal conversation in the early 1980s with Elizabeth Kübler-Ross, when she was invited into hospitals to talk about death and dying. She was amused to discover that a 600-bed hospital had no dying patients in it. She reflected that it is not the dying who have a problem but it is the health professionals who do! This conversion came flooding back to me with such clarity, I noted in my reflexive journal:

> …what would EKR think of this experience today, all these years later – perhaps some things have not improved? Or has our passion for protecting those in our care become misguided? How can I possibly be in a hospice service and find they have no people who are receiving their services, willing to talk about them? A curious moment then unfolds as I walk down the hallway and meet a person arriving into day care today, we great each other and he asks who I am – new to the service or a relative. I explain and he is immediately interested, a retired academic who is living with a life limiting illness, attending day care to give his wife a rest from the physical strain of caring for him daily. He enjoys coming, can talk openly about dying without upsetting his family and can explore experiences of others he engages with during the day care programme. He would like to talk with me and offer back his thoughts on what he calls his “life line service” provided by the hospice. I feel conflicted and excuse myself to check in with the Manager to see if allowable, given the strong message received that there are no people available. The embarrassed dialogue unfolds and I work hard to relax the moment and permission is granted. The interview was brief in respect for his compromised breathing, he tells me he is making an album of memories for his four sons and laughs at the content for the first born and the lack of it for number four, he loves them all equally but the albums are not reflecting that at this point. He doesn’t want to read his transcript, happy to trust me that I have recorded it right but I counter offer and suggest if I send it to him, he may like to include it in the albums and show case to his sons that he was still involved in research right to the end of his life. (personal

> research journal). (this he did do as I was to receive an email shortly after thanking me for this gift to his sons which also captured his thoughts on dying that he felt were more constructive on paper that the emotional challenge of conversations with them as he prepares to leave . . .)

The gatekeeping of the above poignant moment for this man may have lost him this opportunity if it had been upheld.

I was unsure as to the extent of the gate keeping I might encounter and at the time of the above experience, the University of Canterbury media consultant was compiling a media release on work that had been undertaken in the School of Health Sciences, which was to include a project I had undertaken. The human ethics committee gave permission for the article to include an outline of this research project, inviting people to contact me if they wished to talk about their palliative care experience. This had an effect, with people contacting me for more information and expressing willingness to be interviewed. These people were therefore not subjected to any gate keeping.

Having acknowledged above, that there were no changes made to the process of data collection as described earlier, there was in fact a change in the direction the interview took us (the interviewer and interviewee). Participants orientated the questions in a way that I had not fully anticipated. It was as if the philosophy of palliative care was too large to reflect on, so it was physically put to one side (each participant had a paper copy of it) and they chose to talk on an aspect of it, or described it in terms of a story to demonstrate the giving or receiving of care. Roultson (2011) discusses how there are numerous guides for how researchers might engage in interviews to generate quality data. Mostly these guides provide examples of how to deal with the challenges, and it was this challenge I was living, quietly thinking about how to rephrase the question to answer the intended research. After all, the research was being carried out because the phenomenon in question mattered to me. Heideggerian hermeneutic phenomenology presupposes prior understanding on the part of the researcher, refuting the Husserlian notion that it is possible to bracket one’s ‘being in the world’ in the process of philosophical inquiry (Walters, 1995). Therefore, the phenomenological interview based on Heidegger’s philosophy, would incorporate my preconceptions in the data generation. In phenomenology, the interviewer’s task is to facilitate the interviewee’s recall of lived experience and then allow the data gained “to simply speak for itself"' (Oiler 1982, p.179). Dingwall (1997) and Drew (1989) offer guidance from a Heideggerian lens, highlighting that a phenomenological interview is co-created by interviewer and respondent as each one has an effect on the other. I was therefore offered the opportunity to reflect on the reality of what was unfolding and the notion of a co-created interview reinforced a change in direction, if I was open to this construct. By being open to what was important for the participants to speak of, honouring the trust they had in me to share their experiences, we become equal partners in deciding the important question to answer. The interview became co-constructed. Tripp (1983, p.33) offers, a co-constructed interview is more akin to a discussion than a traditional interview. It may be intimate, and as such may reveal other important aspects of the interviewer's views such as malleability, history and permanence (p. 34). Co-constructed interviews allow for both interviewer's and interviewee's voices to be heard, so that my subjective experience may be equally as important as that of the participants, and both viewpoints are truly respected. Holistic person-centred health care is aimed for across the health continuum and has been a feature of the philosophy of palliative care. If we are serious about providing holistic care to our patients and families, then expanding our research methods to explore their lived reality of the 'system' is important, and phenomenology offers one way of engaging in this work and including the researcher's perspective, working in partnership to illuminate a way forward.

Following the interviews, I reflected on the experience, recollecting the content and noting the body language of the participants, utilising my reflexive field journal. This allowed me the opportunity to explore the nuances of the multiple realties from participants, contributing to tacit knowledge. Polanyi (1969) understood that all knowledge consisted of, or is embedded in, processes that could be made possible through tacit knowing, saying "we know more than we tell" (p. 159). He describes two types of tacit knowledge, subsidiary and focal. Subsidiary knowledge occurs when personal experiences are examined, where perceptions enter into conscious awareness. They are visible and can be described, such as noting mood, morale, voice, facial expressions. Focal knowledge includes subliminal knowing, self-esteem, confidence, stress, and optimism as examples, and therefore subsidiary and focal knowledge combine the unseen and invisible aspects of the experience to give a sense of wholeness (Polanyi, 1969). Moustakas (1990) also believes this tacit knowledge could guide the researcher into undiscovered directions and sources of meaning. Believing tacit knowledge precedes intuition he states “intuition guides the researcher in discovering patterns and meanings that will lead to enhanced meanings, and deepened and extended knowledge” (Moustakas, 1990, p. 24).

All participants were offered a copy of their transcribed interviews for their own interest and to check to the accuracy of the transcription. Only one family member willingly took up this offer, as she wished to send it to her sister overseas as a way of sharing the experience, but she did not offer any changes and saw it as a correct record, and stated that she had enjoyed participating. The other, not initially wishing to read his transcript as mentioned above, enjoyed the opportunity to include it as a gift to his sons. No other patient or family member wished to review their transcript. They said they trusted me with the information and were happy that I use anything I found helpful, to benefit others in the future. This is a privileged position to be in, holding the trust of those gracious enough to give of their time and energy, and must be respected, but an understandable stance when time is precious and best spent with family and friends. I did not want to cause additional burden on time by expecting them to read the transcripts, and there may be no advantage realised for them in return for the time and energy required (Abbingdon-Hall, 2002, Hopkinson, Wright, & Corner, 2005).

There was also a high degree of trust offered to me by the health professionals, with the majority declining to review their transcripts. Those who were given the opportunity to confirm or amend the transcripts, agreed with the content and no changes were made. This process was to ensure that their views were not misrepresented and their resulting consent to use the data confirmed the content. Two participants contacted me expressing their delight in reading about these moments in their practice, and said they were going to include the transcripts as part of their professional practice portfolios.

Role as Interviewer

I felt humbled by the health care participants’ willingness to share exemplars of practice and engage in debate over the underlying principles of palliative care and the day-to-day reality of practice. The welcome from consumer participants to their bedside and/or from the bereaved families, was warm and generous with genuine interest in being heard and potentially making a difference for others through sharing their experiences. I considered my role as the interviewer carefully, following the principles developed by Minichiello et al. (1995, p. 61-104), and van Manen (1990, p. 66-68). I was aware of the need for active listening skills, allowing the conversation to develop and being aware of being in the moment with the participant, sensitive to silence, body language, space and respect for the uniqueness of each narrative that unfolded.

Risks to the participants

Some participants became tearful several times during the interview process. During this time, I maintained a respectful silence. When the moment was right in each of these episodes, the participant was able to articulate that it was not distressing to reflect on the experiences but that telling the story brought to the surface the memory of deep love and caring from those who were bereaved, the fragility of life for those who were dying and special moments of care for the health professionals that touched them in some way, and some shed tears of frustration on the challenges of practice.

From the information provided about the study (Appendices C and I) the participants understood that it was possible to feel emotional when talking about sensitive issues, and that support / counselling sessions were available at no financial cost to them. No one felt the need to take up this offer.

The method of enabling contribution to research in a collaborative way, inviting input from consumers and health professionals, is consistent with the philosophy of palliative care which is person-centred and values the bringing together of different ways of knowing in order to take the best course of action. The contribution enables the unfolding of intellectual and emotional understanding that self-interest and interest in others are bound together, and by acting on that understanding we illuminate possibilities for the way forward.

The challenge of too many participants

Purposive sampling was used for this research, that is, the services selected ranged from smaller regional services to larger more comprehensive hospice programmes, and the participants were consumers of palliative care services and health professionals working in palliative care, which ensured participants had rich knowledge and experience of the palliative care phenomena (Mapp, 2008; Polit & Beck, 2012). Phenomenology research sample sizes are smaller than other qualitative designs using content or thematic analysis, the $n = 10$ is common (Groenewald, 2004). Mapp (2008) notes the richness of the data takes precedence over the actual size of the sample. Since the objective is not generalisability, but to illuminate the lived experience and context as much as possible, a small sample size is not seen as a limitation, it is coherent with phenomenological studies that unfold multiple layers of hiddenness of a phenomenon within its context.

The range of health professionals keen to be involved in the study was humbling, and more than were required for the aims of the study and the chosen methodology. These participants were from a variety of palliative care settings, from specialist to generalist services and a mixture of urban and rural settings and I was keen to explore whether there were similarities or differences in these environmental settings, so the larger numbers enabled reflection on these different contexts. I made myself available to everyone who wanted to contribute to the research, which was overwhelming but it felt disrespectful to turn them away. Thirty-eight health professionals were interviewed either one to one or in a focus group situation, where some felt more comfortable “bouncing thoughts around with each other”. As noted, nurses were the dominant profession but there were also participants from many other health professions, as described earlier. Consumers of the palliative care services, were also very keen to participate, and I wished to respect their willingness to share their experiences and not turn anyone away, as their voice is not strongly heard in the research to date in New Zealand. Eleven people who were receiving palliative care consented to being interviewed, but numbers swelled where day care services were running in some centres. With one or two patient participants in day care consenting to being interviewed, word quickly got around that others wanted to offer thoughts too. An informal group engagement took place that was outside the scope originally intended, but I appreciated they needed to be heard. I utilised my reflexive journals to reflect on the insights gained from these gatherings. Twelve family members were also interviewed, they were either caring for a family member, or were recently bereaved. Again, they had experiences from a range of health care settings (home, hospital, and hospice) and also offered experience of palliative care in rural and urban settings. This overwhelming response offered a significant challenge because of the volume of data gathered, and for the process of analysing it which will be discussed in the following chapter.

This chapter has outlined the research design as it was intended and as it eventuated. The following chapter will report on the findings and the analysis of the research.

Chapter 5 The Analysis

We're put here on Earth to learn our own lessons. No one can tell you what your lessons are; it is part of your personal journey to discover them. On these journeys we may be given a lot, or just a little bit, of the things we must grapple with, but never more than we can handle. -Elisabeth Kübler-Ross

Introduction

The previous chapter demonstrated the method of undertaking this research, which resulted in a very large volume of data to analyse. This chapter will address how this was managed.

The aim of the analysis in this research was to unfold and articulate the nature of experiences of people receiving palliative care and those who are providing palliative care. There is no prescribed method for data analysis in hermeneutic phenomenology research (Finlay, 2009). Van Manen (1990) offers suggestions for uncovering thematic aspects of the phenomena. In endeavouring to understand the essence in the narratives of the lived experience I have utilised van Manen's (1990) phenomenological reflective process, the purpose being to "…try to grasp the essential meaning of something" (p. 77). The process of gaining insight into, and explicating the essence of a phenomenon involves: "…reflectively approaching, of clarifying, and of making explicit the structure of meaning of the lived experience" (van Manen 1990, p. 77). To uncover the true 'meaning' of an experience; ultimately means that the themes become the experiential structures of the experience.

> Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure – grasping and formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning. (van Manen; 1990, p. 77)

Themes in phenomenological research have a different meaning to themes identified in other qualitative research methods. In grounded theory, themes are seen as an effort to codify and develop theory, in ethnography, thematic analysis discovers categories that identify and describe cultural groups and practices and in contrast, content analysis may look at the transcripts for certain thematic terms that would show certain concepts (van Manen, 2014). There is now good computer software available to assist these forms of thematic analysis. However, these frameworks of analysis are not commonly considered for phenomenological research, as codification, conceptual abstractions or empirical generalisation cannot produce phenomenological insights and understandings. Interpreting the meanings of a lived experience is a complex and creative process of insightful invention, understanding, discovery and disclosure. It is not a rule bound process, but a free act of “seeing”, meaning that it is driven by epoché (bracketing) and reduction (van Manen, 1977). This also connects with Watson (2012) utilising Husserl’s phenomenological reduction as mentioned on page 63. Van Manen (2014) also explores the notion of phenomenology as a science of examples, meaning the stories of phenomenological analysis may have the status of examples, but he clarifies this as a reflective form of example in order to discover what is exemplary or singular about the phenomenon or event (p. 58).

Extracts from the interviews have been used throughout the text. These provide examples of the participants’ experiences, and may also provoke images of connectedness and understanding for the reader. In asking people to tell the story of their experiences I was asking them to experience a phenomenon which Astrom, et al. (1993) described as: “When it is necessary to report the way it really happened, the natural impulse is to compose a narrative . . . in some kind of temporal sequence. By narrating, meaning is given to lived experience” (p.1 84).

The analysis has been written as hermeneutic text, with extracts of varying lengths from the participants (all names are pseudonyms), literature, and reflections from my field journals interwoven as the essence of the phenomena is considered and explored. All participants were able to describe their experiences of palliative care, with varying degrees of depth within the narrative. Van Manen (1990) provides an assurance that this observation is congruent with life, in saying: “It is true that some descriptions are richer than others. It confirms our experience that in our conversations or dialogues we tend to learn more about life from some people than from others” (p. 92). This observation from van Manen offered reassurance, as I had been tussling with too many participants to do justice to the methodology, as not all offered an in-depth rich description. These less articulate experiences were similar to those of other participants, when I compared and contrasted transcripts as I went back and forth from the part to the whole. This stemmed from the concept of the hermeneutic circle, where the relationship between the whole and the parts is considered, meaning I looked at the whole text to understand the parts, and then at the parts to understand the whole. I have chosen stories of experiences as examples from those with strength of voice to stand in the phenomenological space, but they are supported and backed by others sharing a similar experience, as each transcript was cross checked. This took an inordinate amount of time as I wanted to honour each and every one of the participants and I tussled with how to do that ethically and contain the size of this document.

The analysis unfolds in two parts. The first addressing the importance 'warm up' stories for all three groups (consumers of palliative care services, health professional and the bereaved) before the second part, the hidden stories of silence are revealed by the process of analysis.

The interviews were a humbling experience for me. I held each as a sacred moment. I felt honoured and appreciative that participants in their dying time, and their relatives, were interested in sharing precious moments with me, a stranger, at a personal and intimate time in their lives. For the recently bereaved, who wished to recount their experiences by welcoming me into their vulnerable and lonely worlds of deep loss and sadness, and for my health professional colleagues who made space in their busy work schedules or gave time after hours to engage, and trusted me with the information they were sharing, I was deeply grateful but also acutely aware of the need to respect and care for the information given and for the professional responsibility that goes with it. As I worked with the participants' narratives in accordance with my chosen methodological approach, I was very conscious that these stories were gifted to me and I carried them as sacred contributions to exploring the complexities of the dying time and final acts of living, honouring that for many, these stories were largely untold. In respect of sharing these stories, some of the narratives offered in this section are lengthy but contribute pertinent points.

> *…my thoughts on where we have come from and where we are going in palliative care I've not really shared cos I've been in practice for a while and others probably think it is time I moved on so I am not sure they would listen but if you can do something with them I am really keen to help.*

Nurse transcript

> *It's so personal and you don't talk about it, you try to hold a brave face so you don't upset others, I am grateful for what they do to help so I don't want to burden them with my thoughts' in case they don't come back, I just say "I'm fine thanks" [*uses a steely voice to demonstrate tone*] don't think I've ever really talked in a real way about it. . ..the nurse visits but she comes to see Joe not me, she is busy so I don't like to hold her up.*

Relative transcript

> *It's crazy this dying shit, I'll tell you so you can warn others, I don't talk to my wife, well not in a concise way but I reckon she knows anyway cos we've done this together . . .the Doc gives you the bad news, you feel pretty bloody gutted, . . . you give the chemo a go and that doesn't work . . . you feel pretty bloody gutted again, you end up helpless like this [referring to being in bed in the living room of his house] but the crazy shit thing is, I become a better bloke from it all. Tell me how that happens? Warn others that it does - tell people they can become good guys before they die, I don't know how but do it.*

Patient transcript

Warm up stories

The Patient's Journey.

What is it like to live with a life limiting condition and what is important for us to know about this experience? Like life with its challenges, ups and downs, joy and sadness, complexities, opportunities and possibilities, to name but a few of life's experiences, dying is similar as it is happening to people who are living. Coyle (2006) explored the hard work of living in the face of dying and this was evident for the people gracious enough to share some of their journey with me. As part of the warm up to the interviews people shared their introductory story to palliative care, which ranged in settings from hospital, hospice, aged residential care (ARC) and home care services and led into articulating their experience of the hospice (or palliative care) service and the philosophy of care, and what was important for them.

Creating a warm, supportive and encouraging connection between interviewer and interviewee within the first few minutes of meeting is crucial for a safe and successful interview (Ritchie & Lewis, 2005). In this introductory phase the interviewer is also being observed and evaluated (Patton, 2002). I was interviewing people on a subject that was emotional, personal and intimate and therefore allowing the participants to take me on a journey with a warm-up story allowed time for them to observe my reactions and attentiveness so they controlled how safe they felt about how and what they shared. As Mason (2002) suggests, the researcher has to live through and manage the relationship and situation in a process which is simultaneously personal, physical and intellectual. I also had the opportunity to adjust my relationship accordingly. This reflexive approach to interviewing is a collaborative process, an active co-construction between interviewer and interviewee (Holstein & Grubrium, 2004, Roulston, 2006, 2011) as outlined in the methods section. Dingwall (1997) and Drew (1989) also consider from a Heideggerian lens, a phenomenological interview is co-created by interviewer and respondent as each one has an effect on the other.

> *I've always been a healthy person, very healthy, physically fit due to my work, shearing and all those sort of things. But then prostate cancer struck and a cancer in my bowel and it burst and I had a stint in the hospital. The hospital were very, very good and very caring and the nurses here are just absolutely brilliant. Now you do notice the difference between one or two nurses like, you know, some give that wee bit of extra but you can't teach that. That's either there or it's not there. That's the way I see it. Two of the nurses sat on my bed and said they wanted me to be referred to the palliative care team, I didn't know what they did but I knew I was not going to get better when you get cancer so I had, not a shock but I thought, all this is to measure up a box for me, drop off the perch, but it's not at all. I've learnt that, you know, you're there to help rather than anything else.* (Shaun)

The two hospital nurses who sat on the bed to talk about a palliative care referral were noted as caring and there to help. The diagnosis was a shock but Shaun learns that the palliative care team are there for support. By developing a caring connection, the nurses are able to support the patient's understanding and be with him during the time of uncertainty and not knowing. Shock was also experienced in the following patient's story, but shock in a positive sense of discovering some benefits of being referred to the service.

> *Didn't know much about the hospice before I came in. I knew it was a great place and well organised, I'd heard that but they were always requiring funding, so I didn't know how good or developed it would be really, I didn't really know. I had never set foot on the place, didn't realise what was there. I just couldn't believe it when I walked around and, oh wheel chaired around, and yes I just couldn't believe it when they talked about what they did, it took a bit to get my head around it. I went into shock when they told me a hospice nurse could visit me at home*

> *too. Something that was a wee way away but I could have respite too, go in for a break for my daughter. And then I started to learn how the wheels turned here and it's a fabulous place. Not just for people to come in here to pass away but that we can have a place like this in our town that cares about people. You do see patients who are fading, sad, but it's not everyone. They do an amazing job.* (Pauline)

Although Pauline was delighted to learn how helpful the service could be for her and her daughter I was struck by her initial concern about hospice always requiring funding and leading her to feel cautious about how developed it was going to be. I noted in my field journal:

> A learning moment from Pauline today, have I considered before, the impact of hospice fundraising on the community in terms of what it means about the quality of service? We do it out of need to top up the shortfall of Government funding but we also see it as a way of engaging the community, getting them involved and hopefully providing an educational opportunity, I wonder how many feel like Pauline? Can they feel secure in entering a health care service that is seen as underfunded? If being referred to the palliative care team in hospital which is funded as part of the DHB service, is there a concern when entering a hospice service in the community where fundraising happens, that hospices are underfunded and therefore under resourced in terms of care? How are the district services viewed then? Should this be a concern for the consumers of these services when they are unwell? This adds another level of burden at a vulnerable time in their lives if they have these concerns.

> *Well first of all I didn't really know about the hospice. I understood the hospice was a place, you know that took you in and then you died. But it's not. It's most wonderful organisation and the support to me has been absolutely wonderful. I was diagnosed with cancer. And then I had my appointment for the doctor to have a pre-medical examination before the operation and I had a stroke. So of course because being my age I didn't want to take a risk and about a fortnight later I had another one. So that's my lot. And anyway the hospice, I went into the hospice for a week. They took me in and diagnosed me, you know, but it was wonderful experience. The care and attention was absolutely marvellous. Now I have nurses come three times a week to see me. And I also have the health nurse comes every day to shower me and do things I need. But of course they*

> *don't get paid enough. Very, very poor pay. That's something that should be looked into because they are special people that do this work. They are special people. Stress that will you? The kindness that they all, you know, show, they are intimately involved and they understand you and you can talk to them. You know, some people you can't talk to. But they are, there for you and I found that to be very helpful.* (Beryl)

Beryl's experience was similar to Pauline's in that she did not have a helpful understanding of Hospice prior to being referred or admitted into hospice care. Being viewed as a place to die is a commonly held belief within society, and one which clinicians have struggled with over the years when trying to suggest to a person that they may benefit from some time in a hospice. Once they have had the experience they often wished they had been referred earlier. This continuing challenge has given rise to questioning how best to market hospice palliative care services, identifying enablers and barriers to referrals and dispelling myths and mystery of what happens behind these doors. For Gareth below, the positive advantage of hospice was the home care service and day care that he found so helpful. These services can also be a helpful way to engage people, and therefore they are less concerned about being admitted as an inpatient. He knows the staff and notes the 'hard cases' referring to the fun he enjoys on his visits, and he values how the service is inclusive of family.

> *So I've used this service for respite care, and obviously day care now. Because I come here for the day programme they were able to assess me and look at me and I'd bring up any concerns. They have assessed what I've got at home and because my condition is slow as far as motor neurone was concerned the hospital had done a really good job at putting things in place at home. Once the hospice saw that I had these facilities they realised that it was easier for me to, you know, do all my things that I needed to do and had the carers in place. Although after my shock that my balance had become a lot worse, they gave me another diagnosis associated with motor neurone called neuropathy, clearly one problem wasn't enough. And so that was a shock and again through the loss of balance I have total support groups, two carers at a time. So they were instrumental in making sure that I had enough things in place to stay at home. They come and put me to bed to have an afternoon sleep even, there is a constant stream of people coming to the house to help me and yes, so palliative care is pretty good. And of course the other times I can get here [referring to the hospice] for respite. Which again helpful to give my wife some time off and they look for problems like skin problems or seeing how I cope with strength and toileting and things like that. Yes, they're a good team here, yes. And some hard cases, we have a lot of fun. (…) one of the other chaps in day care, his wife came in and said she was going to see the counsellor and she sort of made a little bit of a thing of it and I thought is it that, that you're indicating that you might like some help? My brain was ticking over so I asked to see the social worker, I know this lady quite likes talking to the*

> *family and they do talk to the family. I go home and tell my wife, "go and have a cup of tea, have a chat and learn all about what's going on." "I don't need to do that" she said. And yet when my day care friend indicated that she was having some counselling of some sort and it just sort of helped her I hoped my wife might be helped too. So I've left it with her to just to know these things are still available to her as well as me. They are interested in the whole family here, that's my story.* (Gareth)

Edith shares her story of being involved with both her husband and son. For her husband, the biography service referred to below was helpful before his dying mind fully succumbed to dementia. He was supported to tell his life story. She knows they will provide additional help when she is struggling to manage his care herself. Life's challenges unfold that her son has Downs Syndrome. He was living in an intellectually handicapped home until his health issues required more oversight and he was transferred to an ARC facility for palliative care, despite being under 65 years of age.

> *I've actually been involved with it twice because my husband's also pretty sick and he has a serious heart condition and a respiratory condition and he's also got some vascular dementia and it was the heart specialist who said there's nothing more that they can do and he referred him to the palliative care team. But at the moment they were really, really good and they provided somebody to come and do the biography for him and the hospice, there's a volunteer visitor that, you know, comes to see him. At the moment he's not needing any of the nurses to come through because he's sort of stabilised and so, but it's there if we ever sort of, if things go downhill and, you know, if he needs more help. So that was my first knowledge, of hospice (…) But my next experience of course is with [son]. That has obviously meant more actual usage of the nurses. He's been in here [ARC] since [two months] so, just trying to think when we were first, it was the oncologist who referred us to the palliative care team. And it was the hospice doctor who visited him when he was living in an IHC home and it was the hospice doctor that came out and said no you need to be in somewhere like this [ARC] and that happened very quickly. Yes, it's been very helpful, very nice and very understanding. Yes. (…) Well it was a really strange thing that we found out that he was so sick because twice he was sent to the hospital from the IHC home complaining of what they thought was chest pains. But it turned out to be gall stones. You know, even with gall stones you get that terrible pain and an hour later, I mean it's gone and you know. And because he had downs syndrome and obviously a form of from dementia starting, nobody pieced all the pieces together. But on one night I'd already been in A&E twice two nights before and they rang from the house and said look he was in such pain I went up and got him and I said ok you know, we'll go down again [to the hospital]. And I gathered up my daughter on the way because I knew, because he was really crying with pain this night and I thought I'll never get him from the car into A&E on my own, my husband was too sick to help and his dementia, he knows nothing. (…) and I said to her oh look it's Saturday night, it's pouring with rain, don't let's go to A&E we'll go to an afterhours doctor which wasn't far from the hospital. And so we did and*

> *there was this was a young Asian guy and he sat there looking at [son] and he sat there looking at him and then he tapped him, sort of got of all the medical history and he went straight over to him and felt his neck and he said "this man very sick". "He's very sick". And I said, "but you know he does have a thyroid condition is that it"? And he said "no, no, no this is really, really serious" and he said "and, you know, you must go and see your GP as soon as possible and, you know, I could be wrong, I hope I'm wrong but you know, I don't think so". And [Daughter] and I sort of looked at him and he said again "he's really serious and sick". And I said "so what would the timeframe be and he said he said he maybe live few months, survival, and then, you know, he will die". And it's just really gone from there, but this young Asian Doctor just sort of knew, he was very softly spoken but clear, I liked that, yes kind in his telling us what was going to happen. (…) And I think we all decided that because of the fact that he did have dementia and this cancer was so advanced that I didn't want him to have chemo. I just, I couldn't put him through that. You know? And the oncologist agreed with me. They tried to do a needle biopsy and it was so horrendous, you know? It was awful. And I knew that there was no way now he could have coped with radiation because, you know, he'd, in the past he would have been very co-operative but, you know, he'd got to the point where he wouldn't have been able to have coped like you have to with radiation and so we, as a family, sort of felt that we didn't want to put him through that. You know, anything else that would make life easier but I couldn't put him through chemo. And the oncologist said, "if it makes you feel any better, I really agree and we'll put it through the hospice, palliative care team". And it all moved pretty quickly very, very quickly, now and he's not mobile at all which is really quite difficult now even in the bed to chair, chair to wheelchair, you know. He's eating pureed food only, you know, there's just a downhill run now. You know? He's lovely still, and the staff here are so lovely, they remind me of the Asian doctor who knew what was going to happen, the staff here are from Asia too and they just know like he did, they just know what to do and are so very kind to my lovely boy, he is in the best place now and it won't be long and that is going to be ok because we have all the staff who are such special people. There's a way, they all share a way of speaking. You have it too. It's a gentleness, it's a listening, and awareness of what somebody's going through. But there's a gentleness there that makes the sadness ok.* (Edith)

I was captured by the true grit and strength of character in this petite woman who was juggling her life between the needs of husband and son. She is appreciative of the *gentleness that makes the sadness ok*. She states that *You have it too*. I reflect that as she is telling her story of experiences, she is observing my interaction to assess at some level how safe she feels in the hands of a stranger, a researcher, as she shares the journey of the two loves in her life. The clinical skills and gentle honest truth of the young Asian doctor, the Asian staff in the ARC facility, the kindness, awareness, gentleness, listening and way of speaking, she identifies as the comforters to this situation where she is pleased to be part of this *special place* when her son does not have long to live. Her noting of the Asian health professionals reflects the dominance of internationally qualified health professionals working in ARC in New Zealand (Hughes, 2020).

Mark shares he has a team of three that care for him in his home, he loves company and feels at ease with their ability to listen, he acknowledges they have passion for their work and deliver it in a compassionate way:

> *Up until a month ago I would describe myself as being in good health, oh yes I had cancer but treatment had gone well and I was back to my full and unmoderated life but now my liver has been invaded and there is little point trying to find a treatment to stave off the inevitable. I have been lucky, an extra nine months and now I am face to face with dying. District nurse calls in when I need her which is getting a bit more frequent but she doesn't seem to mind, it's all part of the service she says. The GP comes to on her way home sometimes, just for a chat, I can go to the medical centre too but she provides home care visits so that works for me too. (…) the local vicar also provides palliative care it seems, whether he knows it or not or whether you call it that, I am not involved with the church but we met when I was involved in the local primary school committee and he heard I wasn't well so just called in one day and has kept coming back. It's quite good we talk about everything and nothing he is a good listener, and shows the same kind of, what's the right term . . . respectful intelligent kindness, yes, does that make sense? It's especially good because I am keen on the great Scottish philosopher David Hume who held an opinion about religion that was quite controversial at the time, so I wouldn't want to lose* [vicar] *by bringing that up but Hume also believed that man's passion in life shaped knowledge and I think the people involved in checking in on me are just that – passionate about what they do, and they do it compassionately too.. (…) I've not had much pain to speak of and my spirits are high, I'm that kind of person and I love company so it's good they all call in.*

I am interested in Mark's words '*respectful intelligent kindness',* kindness is generated by intelligent and emotional understanding that self-interest and the interests of others are bound together, it is about connectedness and when we understand this connection, acts of kindness emerge from it. Intelligent application of skills, knowledge, experience and resources are demonstrated in the previous narratives where we hear the health professionals demonstrating respect for those they are caring for.

In the fast pace of change in health services, workforce issues and budget constraints, kindness can be found wanting in in our health services. Ricoeur talks of the loss of 'ethical intention' in public life which threatens kindness, care and generosity as the market culture becomes dominant (Simms, 2002). If I turn to my understanding of

Hermeneutics, it is based on the premise that text says something not only about itself but about the world at large. There at this moment in time, '*respectful intelligent kindness',* is still evident in the care these people are receiving. However, Mavis shares in the following story her challenging start to palliative care. '*Respectful intelligent kindness',* is not always straight forward.

> *I was diagnosed with cancer at* [hospital] *and they said I would be under the palliative care team when I got home as they couldn't treat me. The district nurse came from the GP's rooms to talk with me, she is good and well known in the district, very discreet cos you know in a rural community nothing stays private for long but you never hear anything from* [Nurse] *she never spills the beans and I like that. I didn't want to talk with her though, it was too raw so I told her I would be in touch when I was ready and she was not to contact me until then, and she agreed and left her number on my fridge but then do you know what? A week or ten days later a different nurse comes to see me from palliative care specialist service. I was pretty bloody annoyed and gave her a short sharp shift. She said I had to see her cos she had driven a long way and had a letter to say I needed visiting, well I didn't, and it was her bad luck she had had a long and wasted trip. I rang* [Nurse] *and ticked her off for sending her as I thought we had an agreement – no contact until I said so, but* [Nurse] *said she didn't know anything about it and would be ringing* [specialist service] *to see what was going on. They apparently have to visit if they are asked to but that doesn't mean I have to answer the door. I have calmed down since then but it was not a good start. I don't see them, I want* [Nurse] *she knows her stuff and she can contact them if she wants so long as they don't come to me I'm happy, I want people I know during this dying business, people I trust.*

Whilst this story did not start well, I was pleased to hear this reality. The stories for this research were predominantly positive and heart-warming from the patient participants, grateful for the care and attention they were receiving yet as practitioners, we know we do not always get it right. It is in these moments when our engagement is not as beneficial as intended, we become grounded and learn from the challenges of proving person-centred palliative care. In Mavis' case, the disconnect between the generalist district nurse and the nurse from the specialist service heightened Mavis' anxiety, the way she intended to manage her reality was compromised, but fortunately resolved with the trust she has in her local provider.

These examples of warm up stories from each patient participant flowed freely and assisted in establishing the relationship with me as the researcher. People narrate their past events and experiences for a variety of reasons such as sharing thoughts, feelings, offering information, or justifying their actions and beliefs. Telling their story can also be cathartic. Pennebaker (2000) and Frank (2000) suggest people tell stories to reaffirm, create and possibly redirect the relationship within which the story is told and they also support the notion that telling stories establishes relationships, which is so important in research. Honouring these stories in my role as researcher, develops the trust moment and we become equal partners where the co-constructed interview unfolds. Allowing people to share or reconstruct their life story illuminates deeper meaning which may be understood in a meaningful way (van Manen, 1990).

The Health Professional Journey.

To walk with people on the path to their dying journey is, I believe, to tread on sacred ground. So what are the experiences of caring for people, as guided by the palliative care philosophy like for health professionals? The participants had received a copy of the philosophy prior to being interviewed, which invited them to reflect on their practice of caring prior to our meeting. For the majority of health professional participants, I had already developed a relationship or connection with them over time and to varying degrees so I was not entering the relationship as a stranger. There was already a degree of comfort and trust. However they too had their warm up stories. These demonstrated that the philosophy was too big, all-encompassing and unrealistic for the current realities of practice. Some offered clear succinct thought:

> *It's all changed and we kid ourselves, I have been involved for many years and seen it change, treatment options have got so compromised, especially for the cancer patients so their dying has got more complicated too, nobody challenges when is enough, so instead of getting early referrals and being able to support people 12 months out from the end of their life, they are being treated right up to their death and die without getting their lives in order and the family is not left in a good position either.* (Anne)

> *Our allied health team is being eroded and undervalued, we could do so much more to support those on our books but the money is the issue. It's not about providing holistic care, it's about providing relief of symptoms only these days and the medical and nursing team don't seem to value our input because our skills on the whole (although I am not talking for our physio), resolve emotional, social, and at times financial and of course spiritual care (…) how come these are not seen as important by some members of our team?* (Beth)

> *Despite having a really good philosophy and intention, all comes down to resourcing. And that's the grind of what we do.* (Vicki)

> *What happens with palliative care is whilst it's become this amazing branch of medicine that has grown out of the embryonic need of Western medicine not addressing all issues with patients dying now we have beautiful hospices and we've got a whole philosophy and whilst we're doing great work it is great work only in dealing with physical symptom management.* (Chris)

> *That whole verbalising about the philosophy is tricky, whilst the intention may be at times really good, practicality is not so good.* (Jane)

> *I personally get really overwhelmed when you actually start focussing on the big picture, you know, because Western medicine has a lot to answer for, you know, like I think Western society has a death denying ideology and we don't want to know about that. We've medicalised our bodies so that we no longer have any attachment to them. You know, community, individuals, seek guidance from the medical establishment to do with anything and everything and we no longer take responsibility. It's become complicated.* (Heather)

Other health care professionals, feeling lost for words, chose to offer a narrative example, seeking clarity and hearing aloud their own thoughts to understand the nature of their practice.

> *We live in a really cool age because, you know, us baby boomers we're knowledgeable, we're educated, we're worldly, we've got all the stuff at our disposal and we're doing things differently. Like my mother who's eighty and we have decided that we're not doing dying the usual way. We're not having funerals. You know, so subsequently, you know dying out there is changing. I worked with a patient's family the other day whose mum said I don't want a funeral, you can put my death notice in the paper after you've cremated me and that people can come round home and have drinks. It's about how I want you to celebrate me, it's not about, you know, crying and all that sort of stuff. We need to put dying back in the community and dying at home permits you to be liberated and that liberation allows you to express your own identify and your own mindfulness, or consciousness about dying and for me that's great. And I think as humanitarians we need to support that. Because we have cultural diversity now, you know? And we don't have the religious parameters or the Victorian parameters upon us now. You know like my peer group is made up of all sorts of dynamic, interesting people with lots of different philosophies from people that want to die in the hot pink through to people that will just the typical Christian, religious service. You know, so there's just normal status to it. Within my own social group and I'm in my fifties and the reality is that when my generation is starting to die, we're doing things differently. And actually we want to be at home is my whole philosophy and we need to see dying at home being really supported and not just symptom management, you know, it about the bigger things we don't deal with now. (*Margot)

Here Margot offers the opportunity to reflect on the changing face of dying as the Baby Boomer generation who have grown up challenging societal norms, enter the later stages of life. This offers a moment to consider how this generation may alter their dying time when they have been a generation who championed the civil rights movement, brought free love, contraception, gender issues and sexuality out into the open. They have changed people's views of retirement, working longer, giving back to society and having a strong influence over retirement villages. It is reasonable to suggest how the end of their life is lived out, will be no exception (Ziettlow, 2012).

> *One of the things that I think that's desperately needed is that going back into primary care which is great, so everything will be based around primary, community resourcing which is where I think we need to be, individuals have to take responsibility now for their health and wellness. You know, that's the reality. For some arbitrary reason we took away people's human rights to be responsible you know, we had this paternalistic ideology in health that we knew better and in actual fact we don't. And, you know, the circle's coming back and we can't afford that ideology, you know, that's the reality, we can't resource it and we can't afford it. Subsequently we need to be able to service that somehow, you know, we need to be able to resource that. Because at the end of the day a human will require physical management in one respect and then all the rest of the holistic approach needs to be sourced according to needs, and that can be done in a myriad of ways and the difficulty with the medical, I'll call them the medical community, is that they are very limited and very narrow in their perspective so it is not giving holistic care that we are supposed to.* (Anne)

The emphasis here is on primary health care providing palliative care but stressing the need for adequate resourcing. Anne also acknowledges the need for physical care but based on an holistic approach. As does Meg in her narrative, especially in addressing spirituality.

> *Palliative care is a really interesting terminology and I'm quite interested in the semantics and the linguistics of palliative, I'm not sure that palliative care actually entirely describe the true essence of what is the nature of the end stage of our living because, the more I consider it the more I believe that it's just, well dying, as a transition. It's a transitional state where we leave our physicality more back into a reality which is a spiritual consciousness for want of a better word. I'll call it consciousness. So palliative care for me doesn't express that and the world health philosophy doesn't express that even though it has tokenism when it talks about spiritual matters or embracing the spiritual side of it. We certainly don't do that in western medicine I believe. Palliative care means to palliate, to relieve symptoms, which is good. In practice it doesn't embrace much thereafter and I think palliative care needs to embrace a lot more*. (Meg)

The following two narratives suggest we embrace death and dying, seeing it as a normal process of living and again the need for an holistic approach is highlighted, not just focusing on the physical.

> *Society needs to become more familiar with death and we have lost that familiarity. We no longer appreciate that we are finite, we think we are invincible until someone says actually we're not invincible and we're going to die, you know (. . .) how has it come to be that we need to get a doctor telling an eighty four year old patient that they had cancer and the patient looked blankly at the doctor and said I'm going to die? And the doctor said "Yes". And in a moment the doctor said we're all dying and we all die. That's what we do. And the patient was just kind of surprised at eighty four and, you know, it made me think how does the lady feel, to get to being eighty four and not realise that you're living towards the end of your life? I thought it was really delightful that the doctor said yes we are all going to die. Embracing death, we're not good at it I don't think. I think we can improve upon that. But again that takes energy and a belief system that acknowledges that we're going to die. Which then we have to look at society as becoming more disconnect from nature. So how do you bring that back into balance? With all our systems and if I look at it from the systems approach, the systems are always kind of there that we have to work in but systems don't address the actual core of the issue. I don't think palliative care will actually go far except to put more band aids on top of band aids, on top of band aids. Because the actual core of the issue is not being addressed and that's our humility. And that needs to be addressed.* (Patricia)

> *For my own personal practice there is much to be done and there is much to be gleaned from looking at what we do and how we can do it better. For me working on the coalface going to work every day, we really have to shift our perspectives and palliative care is a doorway that opens that concept and what I experience is that like the World Health Organisation ideology, palliative care every day, when that older person comes to the end stage of their life, in the winter years of their life we are palliating their symptoms. It appears to me that our system doesn't permit people to die easily in one respect and in another respect we're really good. People can die with grace and dignity. We are very fortunate to be here in that respect and we do offer good services. However, you know, like in improving our services there's always much to be improved. We deal with the physical quite well, you know, there is always aspects that need to be improved, but the rest is tokenism, we still don't get it. I have patients that come in and, you know, like everything is pretty focussed on the physical. We deal with pain management, we deal with all the physical side of pain management. We're not very good at any sort of emotional or psychological distress, rituals or any spirituality.* (Sharon)

Julia offers an example of where taking time and good communication can have a good outcome for all concerned.

> *I was going on the afternoon shift, then the patient had arrived from the rest home with her daughter and she'd had a fall and it was obvious that she was dying. And I spoke to the daughter and said "how do you feel?" You know, here's your*

> *mum, she's come from a rest home, she's ninety odd, you know, because she was in her nineties, she'd had a massive fall, and we talked about the service that was being offered and you know, the hospital has this policy whereby we can do everything, you know, do the x-rays, put an IV line in, give her fluids, check everything continually take her observations, you know. What did her mum want? What did she want? As a family, what were their thoughts? I explained that the hospital would treat in a curative fashion and try and get your mum right. And yet it was obvious to the daughter that her mum was dying too. But what was interesting was that the rest home that she lived in couldn't or didn't permit people to die because it wasn't a hospital level rest home, it was just a regular rest home and so that brought up a whole lot of issues. But anyway she physically had nowhere to die except come into hospital so she came in. And I really batted for her, I went to the house surgeon and I said this lady is dying. I've spoken to the daughter, we want a comfort care approach. And bless that house surgeon, she looked at the patient and she agreed and she rang her registrar who rang her consultant and said this is what everyone wishes and so we didn't do anything with regard to trying to cure that woman of her dying process. We went straight into the comfort care process and that woman died, twelve hours later, having beautiful pain relief, having a beautiful non-intrusive respectful death in a hospital setting. So that was fantastic. And that just proved to me as a nurse, we can advocate. And, but you need doctors to listen. And bless everyone who listened in that particular incident.* (Julia)

These examples of warm-up stories from health care professionals began to reveal that the participants needed to talk about the challenges, acknowledging physical care was addressed but that the holistic lens was not being applied. They were living with challenges to service provision through budget constraints, time pressures, and the changing face of society as it denies or challenges new ways to end of life care. There was perhaps an ease in being able to talk about these challenges as I was coming from a position of knowing, a shared understanding of their lived reality. It afforded me the opportunity to reflect on how to reword my interview questions to reveal the heart of what was important to their practice in the midst of all the challenges.

The Bereaved Journey.

The philosophy of palliative care provides for the care of family after death, to offer support during bereavement. There is however, a tendency to conceptualise the bereaved as a vulnerable group needing protection from research (Payne & Field, 2004). There is evidence in the literature to also suggest that ethics committees are paternalistic and obstructive when researchers are seeking approval to research the bereaved (Gallagher, 2010, Chalmers, 2011, Juritzen, Grimen, & Heggen, 2011, Panagua, 2012, Iphofen & Tolich 2018). Whilst they have an important role to play in protecting people from harm during research, it is questionable whether they should be able to decide on behalf of people who are capable of making an informed choice whether to be involved or not. Rather than being concerned that researching death and bereavement may result in harm, we must consider the benefits and give the bereaved a voice. The process of telling their stories can be therapeutic despite the emotional impact of reliving painful memories (Crowther & Lloyd-Williams, 2012). Without a voice from this group of people we rely on theories and constructs to support the bereaved, and as such pathologise a normal and natural grief reaction to losing someone we care deeply for. A study by Crowther and Lloyd-Williams (2012) demonstrated that out of 41 participants ranging in age from 18 – 86 years and from different socio-economic backgrounds, the key point was, that they wanted to be heard despite the emotional journey in telling their story. There was a sense of inner peace from doing so, and they hoped it might be beneficial to others.

Three bereaved families consented to being interviewed. I was invited into the home of each family group by the surviving spouse who had invited their adult children to be present for support in two situations and a neighbour was invited to support the third. The interview took place between three and five months from the death of their family member/friend. These interviews were longer in duration than the patient and health carer interviews as they had a need for me to know something about the person who had died before talking about their experiences. The warm-up story included such topics as how they met, travels, jobs, family, illness, treatment and coming to terms with the end of life as they knew it as a family. At times there were interjections to 'straighten the facts out' important to some present, to 'get it right'. But any story told in this context is a construction, recognising that the story reflects the storyteller's point of view, it is unique to them, based on their reality. I am aware the story told to me that day, will change over time, it is an ongoing process. As it is retold time and time again, new understandings emerge or different meanings are ascribed that were not there initially. Van Manen (1990) also acknowledges this by suggesting that people cannot reflect on a lived experience while living through it as the experience changes or dissipates. For the bereaved participants in this study, recounting their experience of receiving palliative care for their spouse, while still living though it by receiving bereavement support, provided insights into the nature of the experience. Van Manen

(1990) states “the essence or nature of an experience has been adequately described in language if the description reawakens or shows us the lived quality and significance in a fuller or deeper manner” (p. 11). There were tears of sadness and some light-hearted moments as I observed support members working to lighten the atmosphere at times. There were also tears of love and remembering as I noted in my journal:

> My time listening to Mary’s story today of the death of Bob was interrupted suddenly by the music softly in the background from the classical radio station. “Wait a minute” she says as she relaxed back in her easy chair, eyes closed. Her daughter looking at me for reassurance, unaware of what was happening, a moment of awkwardness etched on her questioning brow. I bring my finger to my closed mouth in a sign to remain silent and we wait. Tears slowly run down Mary’s face and she begins to smile. Daughter gives a quizzical jerk of her head, we wait . . . The radio announcer breaks the silence by announcing the composer and the key the music is played in. Mary comes back into the room from her time out. Tears still evident as she informs us that that was the music played at a tea dance when she met Bob. She describes the place, the atmosphere and his gentle handling of her as he serenades her on the dance floor. He was a gentleman she tells us but with a twinkle in his eye, he was courting her. Her tears were positively greeted as she is taken back in time to the beginning of their romance, she “loved that music” and was also amazed it should play while we were talking about him, she saw it as “a sign that he was with her” that it was “meant to be,” that we were talking today. Her daughter gave a brief laugh of relief and enjoyed hearing the story of her Dad, one that she had not heard before, sparked by a memory embedded in music.

Conclusion from warm-up stories

Warm-up stories were important to all three groups of participants. It enabled the opportunity to develop rapport, respect and a trusting relationship to unfold between us (researcher/ participant) before getting to the heart of each interview. The stories also helped establish a comfortable and safe environment for sharing participants’ experiences of giving and receiving palliative care. It offered me as the researcher an opportunity to observe and reflect on each individual engagement so that I could consider adjusting my approach or rephrase a question to best connect with the person I was interviewing. This ability to develop an effective and trusting relationship comes from my experience as a palliative care nurse in clinical practice where the nurse-patient-family relationship are hallmarked by respect, trust, inclusiveness and rapport (Dahlin, 2016; Epstein & Street, 2007). Canning, Rosenberg and Yates (2007) consider these skills as a critical foundation of specialist palliative care nursing. This respectful connection is not a given, it must be co-created. At times it is easy and effortless, as with my colleagues as we shared a familiar understanding of palliative care and the client groups we care for, but for the patient/family connection, extra care and attention were required from the very first steps of a warm smile on greeting and portraying a respectful presence as we find a meaningful way to connect. Buber (1959) acknowledges this connection by saying “it is a grace, for which one must always be ready, and which one never gains an assured possession” (p. 131). And Ricard (2015) offers “Human beings have a profound need to feel connected, to trust others and be trusted by them, to love and be loved in return”, (p. 281).

Illuminating the hidden stories

Rager (2005) offers "Qualitative enquiry is not a purely intellectual exercise, but rather one for which researchers enter the world of their participants and, at least for a time, see life through their eyes" (p. 24). As I held each person’s experience of tussling with the day-to-day realities which are variable and complex, I observed how people interpret various aspects of their lives. I followed a process of trying to uncover the essential aspects of the phenomena by reading and re-reading the narrative; listening and re-listening to the taped interview, recognizing that: “…the realm of meaning is best captured through the qualitative nuances of its expression in ordinary language” (Polkinghorne, 1988, p. 10). I wished to enter into each individual’s story as a whole, and as parts of the whole; going on to look at a collective of people sharing a common experience – that of being in the world of palliative care. By doing this, I was aiming “…at elucidating those phenomenological structural features of a phenomenon that help to make visible, as it were, that which constitutes the nature or essence of the phenomenon” (van Manen, 1984, p. 27). This technique takes time, is messy and requires long periods of being fully immersed in the process to tussle with the possibilities as each word is looked at and heard, then phrases, and then stepping out and into the big picture and asking “what is going on here?” and “what is this example, an example of?” (van Manen, 1990, p. 86). As I wove into and out of the text, interviews that followed on from the warm-up stories, and reflection on and in the process, there became a new sense of what these narratives meant, the uniqueness, the similarities and the differences and in turn the sameness of the differences of each story.

In aiming to unfold and articulate the nature of experiences from people receiving palliative care and those who were providing palliative care firmly in my mind, I struggled with what appeared to be a mismatch between what I was asking of participants and what I was receiving. I was being taken on a journey of deeper discovery about what was important to them, the phenomena of right relationships, compassion, connection and silence as a powerful form of communication and care, revealing their connectivity to all groups and stimulating my own reflection on the value of these essential qualities of care in the final acts of living. In discerning this, I gave meaning to the idea of “different kinds of reality”, and “…the emergence of multiple realities” (Polkinghorne, 1988, p. 1), rather than the belief that there is only one interpretation or experience of reality. Frank (1995, p. 58) describes the phenomenon of ‘multiple realities’ as the ‘interrupted story’.

As I attended to uncovering thoughtful meaning to each experience I had to do so with openness as “we are always being and becoming” (Munhall, 1994, p. 215). I had for a time not been as open to what was being revealed as I thought I had been, and therefore risked not clearly seeing what was being gifted to me. Writing thoughts and insights in my reflexive field journals as emerging themes were revealing themselves and in discussion with my supervisors for additional clarity added to the rigour of unfolding a new sense of participant truths. I tussled with the original focus and working title of this research, “Communities of care: supporting people living with their dying”. Stating in the information sheets: “This research is undertaken in order to seek a way forward for palliative care in our community and enables reflection on current service delivery and review of the philosophy of palliative care that underpins current practice” (See appendix A). I needed to refocus the lens of inquiry because of what I was hearing and seeing in the participant’s narratives.

Clarke and Braun (2017) offer reassurance that the research question is not fixed and can evolve as the themes reveal themselves, as this is a flexible process. Phenomenology also calls for one to be open to changing directions and exploring the data that are not always obvious at the onset of the research (van Manen, 1997). van Manen also advises keeping two questions in mind (what is the lived experience like and what is the meaning of the experience?) to help focus the analysis and maintain openness to changing direction, so I shifted to asking, what is the lived experience of giving and receiving palliative care? and what is the meaning and significance of the experience? These questions better illuminated the participant's narratives. Once I accepted the hermeneutic nature of the analysis I was reassured by the fluidity of where this research analysis was taking me.

Writing is an inherent part of the analysis process. As van Manen (1990) wrote "human science is a form of writing" (p. 111). Richardson (1994) also supports this by stating "I consider writing as a method of inquiry, a way of finding out about yourself and your topic" (p. 25). In the middle of the messiness of the analysis I did not appreciate Richardson's thoughts as I have always struggled with my writing and was feeling very challenged by not seeing a clear pathway for capturing my thoughts in some coherent order on paper. Van Manen (1990) reminds me that a certain form of consciousness is necessary when reading and writing and it is closely linked to reflection:

> Writing fixes thought on paper. It externalises what in some sense is internal; it distances us from our immediate lived involvements with the things in our world. As we stare at the paper, and stare at what we have written, our objectified thinking now stares back at us. This writing creates the reflective cognitive stance that generally characterizes theoretic attitude in the social science. (p. 125)

I began to write with the intention that the reader would be drawn into the text almost as if entering into dialogue with it. The words and sentences would resonate with the reader's experiences so he/she could begin to see what it means to live these experiences. The interpretive element of hermeneutics explicates meaning and assumptions in the participants' texts that participants themselves may have difficulty in articulating, for example, tacit practice knowledge (Crotty, 1998). Michael Polanyi

(1983) in referring to tacit knowledge notes “we know more than we can tell” (p. 4). He is suggesting tacit knowledge cannot be easily formalised or put into exact words but that it is a feature of our knowledge of that world.

The analysis represents the findings I made at the time this thesis was written up, but I am certain that my thinking, reflection and tussling with ideas and notions will continue for some time yet. van Manen (1999, p. viii) confirms this notion of the continuous circle of understanding, relating to the hermeneutic circle, a metaphor for understanding and interpretation, which is viewed as a movement between the parts (data) and the whole (evolving understanding of the phenomenon), each giving meaning to the other, such that understanding is circular and iterative. Interpretive phenomenological inquiry is based on the idea that no interpretation is ever complete, no explanation of meaning is ever final, no insight is beyond challenge – it behoves us to remain as attentive as possible to life as we live it, and to the infinite variety of possible human experiences and possible explications of those experiences.

The voices of silence

‘Silent moments’ was the overarching essence of appreciative care emerging from the analysis of the transcripts across all three groups, (person receiving care, health professional, bereaved). While it was not always overtly expressed it was present, revealing itself, inviting exploration and consideration for bringing this element of care to the forefront of awareness to assist practice. There is little in the literature that explores silence although Polanyi (1983) reveals silence as tacit knowledge, as intuitive understanding that is less easily put into words. Swift (2014) a healthcare chaplain, offers: “In a world full of productive knowledge and solution focused health care it can be hard to argue for the necessity of space and silence” (p. 167). Yet the value of silence and space is recognized in religious and spiritual traditions, and in a growing body of evidence for meditation and mindfulness practice (Kabat-Zinn, 2005). Aranda (2001) wrote a paper exploring silent voices, hidden practice, that I have often reflected on over the years as I consider the silent and hidden element of skilled nursing that arises from intimate relationships with people I have cared for on their final journey in life. This is a slightly different take on silence than what is explored in this research, but I remain mindful of the hidden dangers if these intimate relationships go underground, and therefore through this lens of concerned awareness I scanned the transcripts for this possibility. Hughes (1985) offers another thought about the lack of awareness of silence suggesting: "'we are so afraid of silence that we chase ourselves from one event to the next in order not to have to spend a moment with ourselves, in order not to have to look at ourselves in the mirror.'" (p. 97). In the following narrative, Sandy (a nurse) is aware of slowing down, being calm and enjoying the possibilities of quiet time . . .

> *I love it when I can just "be" with a person, to step aside from the frenetic pace of our crazy work load and really deliver the care that is really needed. To breathe and use that calmer time to see what is really going on and what is needed. To be still and centred. Yea, see, the other week I went into the room of this woman who was in her final days, she was settled, the family were resting, it was still and quiet, I just eased my way in and sat, didn't talk, you know when there is no need for talking, I was connecting with them in a difference space, they knew I cared by just being there. Actually, as I am telling you this, I'm suddenly thinking, thinking aloud here so it might sound crazy but, if I had broken the silence, I would have interrupted their story, their story is not finished yet but somewhere in this suspended state of waiting for death, there is peace and rest in the middle of things, it would have been disrespectful to have broken it eh? Maintaining that quiet time has powerful implications I think.*

Sandy noticed the room was *still and quiet,* she was being still in herself and for the others. She became fully present and demonstrated her ability to authentically attune to others. This being fully present is an existential stance, the ability to bring her whole self into the moment of others. Denham-Vaughan and Edmond (2010, p. 15) suggest non-verbal communication may be more profound, and the deepest level of connection may only be possible in total stillness and silence. Tornøe, Danbolt, Kvigne, and Sørlie (2014) talk about the nurse's ability to sense the atmosphere in a room and when called upon to be in compassionate silence, with the ability to 'be there' conveying consolation, presencing and companionship, which can aid spiritual or existential suffering. This I was to witness in my visit to a hospice service to interview staff, as I noted in my field journal:

> The interconnection between nurses, nurse manager, mother and son. Mother is restless and agitated despite all the physical assessment skills and considerations to give her relief, the nurses decide medication in the form of a benzodiazepine is required as they wonder whether she is experiencing some sort of emotional or existential pain, they inform the nurse manager. "How about we run a bath first" the Nurse Manager

> replies, they know what that means, they have worked with her for a long time now. Tea light candles surround the room, soft music plays and bubbles almost disguise the bath itself with red rose petals scattered on top of the foam. The petals are rather squashed from the tight chubby fist of 5 year old son who had been led out into the garden by the nurse manager to collect them to make the bathroom "beautiful" for mummy. He chose the red petals as red was her "bestest colour". Mother is wheeled to the bathroom and lifted gently into the foam, the lights dimmed, the atmosphere takes over and she begins to weep. There is no rescuing of the crying, no interruptions, but a respectful silence, allowing her to perhaps assimilate the enormity of what was happening in her life in a way she was not able to, or did not want to give voice to. Son was invited into the bathroom, dignity maintained by the clouds of bubbles "don't cry mummy, I picked the bested colours for you" (a moment of observing the moist eyes of the nurses, knowing he would not have his mother for long) one leaves the room to come back with a plastic jug and invites him to scoop up the water and trickle it around her shoulders, we step out of the room and leave them in peace. Afterwards I invited discussion about this scenario, about what might appear so basic at one level but is immensely complex in another and suggest they write to the son, telling him about the role he played in the final days of his mother's life and that the letter be given to the father to care for until the time is right. By the end of the day the letter is read out to me to seek approval . . . .they exquisitely describe how he chose the rose petals with great care, knowing her "bestest" colour and how he gently and for quite some time poured water around her shoulders, allowing it to wash over her breast less chest (a gentle way of telling him she had breast cancer). They inform him of how she was feeling restless and how powerful his actions had been in assisting her to relax, there was no place for medication, his attention was a powerful and therapeutic act as she looked at him with love, through the eyes that only a mother could have for her son.

We unfold the meaning of this practice,

> *Creating the right environment often helps alleviate problems, I've seen it so many times with* [Nurse Manager] *who reminds us that we have to look deeper at our practice when it is so easy to reach for the drugs. I am so pleased we slowed down today to create this special moment for this family, she was settled after this, (…) will we ever know what she was agitated about? I guess we may never know, we don't really need to know I guess, so long as she finds some sense of peace or understanding for a time at least.* (Gill)

> *Yes I agree, when you can create a peaceful environment, at some level healing occurs, words are tricky to describe what happens, silence and peace can be great healers. The pace of life in health these days we find chaotic never mind the patients so when we can slow down, everyone benefits, them and us.* (Pippa)

Tornøe et al. (2014) discuss the power of consoling presence in spiritual or existential distress, their research highlighted this phenomenon for hospice nurses caring for the dying, maybe this presencing was also what was observed in the connection between mother and son as he quietly and rhythmically soothed her physical body with warm water, unaware of his therapeutic impact both physically and emotionally but in this shared silence, they both connected. Seen in this light silence can be a powerful source of peace.

Silence as suffering and compassion

There is another kind of silence we must acknowledge—a dark silence, a silence of truths unspoken and stories untold. It is a silence held in the shadow of emotions too painful to bear, too deep to speak of. Perhaps at first, silence can be protective, allowing us to escape the overwhelming grief that threatens the potential of our future, but as time goes on, and the silence deepens, it becomes an inescapable silence, a silence of doom. If we look deeper into the comment from (Gill) when she says '*will we ever know what she was agitated about? I guess we may never know, we don't really need to know I guess, so long as she finds some sense of peace or understanding for a time at least'.* Here we see that this peaceful state may not last. Is her silence hidden in her emotions, too painful to bare, a dark side to silence from the untold truths, dark secrets, and overwhelming grief and despair so that silence becomes inescapable? Kierkegaard (1980) considered this form of despair, a sickness unto death, but also suggests silence as an opening to possibilities, noting that countless poets and purveyors of tragedy have seen it this way, such as C. S. Lewis, Viktor Fankl, Paul Tillich, Shakespeare to name a few, offering the opportunity to find meaning in the darkness.

The following narrative from a mother and daughter interview following the death of their father/husband offers a brief moment of silent distress and anxious looks between them and the district nurse as the ability to keep their father/husband at home, comes under threat, yet in that silent moment for the Nurse, a creative possibility emerges:

> *We were both so tired from endless nights of broken sleep, that the hardest you know, it was a killer for me, God knows how mum seemed to be doing it better than me, she was nearly 80. (…)* [District Nurse] *called* [specialist palliative care nurse] *to see if there was something she could offer for Dads restlessness but when she saw how tired we all were, well she was a bit cross with* [District Nurse] *saying Dad should be admitted to* [Hospice] *so we could get some rest, she didn't even give us any choice, she got her cell phone out and began to make a call! Mum and I just looked at each other in silent horror, we couldn't have that, we had agreed he was not going anywhere, we would manage, it was really awful and* [District Nurse] *looked at us in despair too I reckon. Then whammo!* [District Nurse] *says, maybe there is another way. (…) my sister is in the UK, she couldn't get back to see Dad and she felt helpless and suffering from not being with us, we have all been so close* [District Nurse] *suggested she give us a break using the iPad. (…)* [Sister] *had an office job, computer work, and had her laptop connected in to watch Dad through the iPad beside his bed. Mum and I could go to bed and sleep and if Dad was restless or anything she would ring on the landline to wake us up and we would go and see what he needed. I don't think we slept really that first night to be honest, but the next night Dad wanted to get up to the loo, she rang us, Mum took him to the loo and settled him back into bed and knowing, proving the system would work, the next couple of nights we did actually sleep. That's all we needed and* [Sister] *felt good about helping us and when Dad was awake, she could talk with him, they both enjoyed that time together. I'm so pleased* [District Nurse] *came up with that suggestion, it worked really well and did mean we could keep Dad at home to die as we had promised.* (Gail)

There was no place for words in the *silent horror* of what was unfolding in front of them. Daughter in the UK *felt helpless and suffering from not being with us,* was suddenly able to provide a valuable and worthwhile way to support her sister and mother, when a creative solution was mooted by the district nurse, giving her meaningful time with her father. The district nurse involved in this episode of care commented:

> *the problem is families have no roadmap for navigating these experiences, we need to do that for them, we have been in this place many times before but this is unique for them. I think I was tired that day, I had been concerned for the clear*

> *exhaustion that they were experiencing but I knew their wishes and each time I broached the idea of a break, the conversation was shut down quickly. In my tiredness I wasn't prepared for the way [specialist palliative care nurse] reacted, that's not normally their way (…) I felt numbed into silence, so broadsided that I couldn't think or act quickly and kinda felt caught between what I knew this family wanted and yet I had asked [specialist palliative care nurse] to visit and I was thinking she wouldn't appreciate me standing against her suggestion. Ahhh that position of being between a rock and a hard place, I could see [mother and daughter] pleading for help, not in so many words, it was the look of panic in their eyes I knew they needed me to sort this and somehow in my frenzied state, this idea came from nowhere – technology was the answer.* (Denise)

This is one of many examples of suffering at the end of life. DeBellis et al. (1986) supports my clinical experience of suffering by indicating pain, loss, disability, chronic illness, inadequate symptom management, the effects of illness on family and friends, life limiting outlooks are just some of the reasons people suffer. Cassell's (1976) seminal work on the topic, adds that suffering comes from the person's perception that they are disintegrating, losing physical integrity and impending destruction of identity. Byock (1997) extends this by including suffering occurs when a person's emotional pain is not understood. The relationship between physical pain and suffering is complex. However complete physical pain management cannot be completely achieved without addressing the emotional, psychological or spiritual pain, that is suffering. The challenge to many of us in practice is how 'to be' with people in their suffering, we can so often feel awkward or helpless, it is hard to be with people for whom we only offer our presence. If we can remember, our presence and the willingness to share our basic humanity can be a healing experience for those we are with and it can be sustaining for ourselves. This silent presence enables the person to tell their story and in doing so often find meaning in it. Neimeyer (2001) refers to this as 'meaning making' in the context of suffering.

Tom, a community Pharmacist who is a member of the palliative care services in his region offered an experience of suffering from his team's perspective when caring for a family.

> *Yes, so the young mum, three kids, three young kids, and she'd fought very, very hard to stay in the job as long as she could, she did amazingly well. Our whole team got right behind and supported her. They lived a long way out of town so everything had to be in a courier at a certain time and so everybody was well aware of this because if they didn't get it she was going to be in pain. So that worked fine, in fact we did really, really well, the whole team did amazingly well*

> *for that. But she'd come in and see us and emotionally it upset the staff because they're young mums themselves and they found it very, very difficult emotionally, lost quite a bit of sleep over it, there was a lot of silent suffering as they identified with her situation so when I discovered that, we ended up having to get some counselling to work through those issues and it's a base fear isn't it if you're a mum that you get cancer have anybody to look after them and that, yes so, but they're a great team who care about people they are really compassionate and that's what's really important because caring and compassion is what I'm about. The father came in after the funeral and he just thanked us, you know, just asked, was there anything we needed, he was being caring and compassionate back. When we have a close association and we always feel sad when people pass on but we also know it's a good thing for the person is out of pain, but this one we were conflicted with feeling for the children and the husband and the whole family dynamics and everything like that.*

Tom offered in his narrative a very real example of the challenges of caring for someone when we can identify in some way, with their situation. It can be a look as you walk past the end of a bed, through to sharing a similar age and stage in life. In this case Tom's staff, females with young families, are caring for a woman, her husband and young family. What affects our clinical interventions the most, are our personal feelings and working with people who are dying confronts us with our own mortality. Tom picks up on the *silent suffering* of his team and arranges counselling to support them all. Our very real and often intense reactions to caring for the dying tell us that there is a person-professional interface between our own life developmental tasks and our professional interactions (Genevay & Katz, 1990). In this field of profoundly privileged work, how often do we stop and reflect on the connection between our personal lives and those people we are caring for? Reflective practice and professional supervision have been critical in some of the helping professions such as social workers, counsellors, psychologists, and mental health nurses. This has not extended to all professional groups. If we have not examined the many facets that affect our thinking, feeling and behaviours, how do we begin to believe we are caring appropriately?

I raise this question constantly with my colleagues as we come together to share our learning in post-graduate studies and ask, how can we begin to care for another if we do not do the self-work and care about ourselves? I can receive comment in return that this is personal and we are doing professional work. I argue that this personal work is professional. Our professional role in caring for the dying and the bereaved is extremely personal in nature, we are profoundly influenced by these families as much as they are influenced by us. Our emotional response to what is unfolding before us affects our clinical decision making whether or not we want it to, whether we admit to it, or whether we are even aware of it. A student colleague offered comment on this aspect suggesting in our caring for a person in distress and agitation and wishing for their peace and calm, we reach for medication to sedate, often to appease ourselves, and without consciously doing so, we silence the agitation for our own needs as much as the family's needs. She offered a challenge in the form of a poem to invite a moment of reflection:

When I am Cold and Frightened

When I am cold and frightened
and call your name
or get out of bed to find you
because I can't find my bell

Don't reach for the midazolam
reach for me

Reach out and touch my skin
there's a warm heart inside this body
that has beaten through many a storm
If you touch my arm you might find its pulse
and know that at times I might be a little weak
at times a little confused but
that deep down
in my very soul
I am strong

Take five minutes from your busy day
come find out what make me "beat"
tell me your story
listen to mine

tell me of your children
of your new love
your new car
and your new red skirt

I'll tell you of my dreams
cos, my new love, my red skirt
and the paint on my new car
have faded now

I'll tell you of the things I dream of
as I lie here waiting for
the angels to come

I dream of sunshine
on my face
and on my hands

I dream of warmth
your warm hand in mine
the soft blanket caressing my chin

I dream of music
gentle rain droppy music
played by violins and a harp

If I could have just one of these things
by my side
perhaps, and just perhaps
I'd be calm and wait my turn for the angels

Perhaps, and just perhaps
I'd call you one more time
cos I do love how

your touch, your voice, your warmth
can take away the cold, the loneliness and the fear

Don't reach for the midazolam
reach for me (Mary)

If we have the courage to confront the complexities of our responses and interactions we can use it to inform and enrich our work, to grow personally and professionally.

Tom also offered in his narrative, a heart wrenching story, which can also be viewed as an everyday story of working in the shadow of dying, that of providing compassionate care:

> *they're a great team who care about people they are really compassionate and that's what's really important because caring and compassion is what I'm about. The father came in after the funeral and he just thanked us, you know, just asked, was there anything we needed, he was being caring and compassionate back.*

Sasser and Puchalski (2010) suggest compassion provides the unspoken language to address unspeakable suffering (p. 937). Compassion creates an environment of trust between the health care professional and the consumers of their services. It is the essence of person-centred care, where one is heard as a person, and not as a patient or illness, or a group of complex symptoms. Providing a definition of compassion is complex because of its moral and spiritual values (Schantz, 2007). It is interconnected between the person who is suffering and the person witnessing it, as Gallagher (2009) offers, "compassion responds to the pain it can see with its eyes, and its natural expression is the embrace of care" (p. 239). Compassion also mirrors complex concepts in their own right. It has been considered in the context of power (Wishart, 2005), silence (Back, et al. 2009), love (Leathard, 2004), presence (Sabo, 2008), care (Dewar et al., 2014), altruism (Saslow et al., (2013) and political virtue (Whitebrook, 2002). It is the writings of Nouwen, McNeill and Morrison (1982) that resonate from a personal experience of compassion at the end of life, when they suggest, "compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish . . . compassion means full immersion in the condition of being human" (p. 4). Compassion as our inner guide offers discernment on when and how to act in certain circumstances and opens the wider debates of the meaning of pain, the challenge of facing suffering and what it means to be human in the context of clinical care delivery.

Cecily Saunders believed that the way care is given can reach the most hidden places (Saunders, 1996), suggesting palliative care can make a difference by our willingness to engage carefully and purposefully to meet the needs both visible and obscured. Nouwen et al. (1982) offer that when the humanity and vulnerability of the practitioner and person receiving care are held in equal measure, a core message for both compassion and palliative and end-of-life care is confirmed. It is however, not without its risks, as compassion requires fortitude, resilience and sometimes risk taking, but always tenacity and determination (Larkin, 2015).

Silence as connection

Picard (1952) offered some of the earliest writings on silence in 1848 but these did not appear in English until 1952. Picard describes silence as “an autonomous phenomenon”, which is “not simply what happens when we stop talking”. For him, silence is an essence, which is spiritual rather than material, “an independent whole, subsisting in and through itself” (p. 15). He suggests silence is the firstborn of the basic phenomena, it envelops the other basic phenomena of love, loyalty, and death. For him, it connects past and future, God and the individual. His existentialist approach is an example of how certain believers attach a theological value to silence. Thomas Merton, who was greatly influenced by Picard’s writing, believed that silence “is necessary for the restoration of authentic communication” (Matthews, 2002, p. 62). Bassett, Bingley, and Brearley (2018), explored the nature, meaning and value of silence in palliative spiritual care, interviewing 15 palliative care chaplains. ‘Spiritual caregiving silence’ emerged as a person-centred phenomenon that supports patients and their relatives, evoking a sense of companionship and connection. (p. 34). Their research offers examples of how silence contributes to caregiving at the end of life: as a way of being with another person, silence can offer comfortable companionship; as silence deepens, a sense of intimacy and connection occurs with the ability to facilitate change. They acknowledge that these insights, from chaplains, may also resonate with other professional care givers, inviting us to reflect and consider these findings to further deepen understanding to benefit patient care (p. 46).

Glenda offers her thoughts as a Hospice Chaplin in this research . . .

> *Recently I picked up a pamphlet, that's available out on the main counter at hospice and it aims at talking about the holistic care that's provided and planning for practical matters as well as addressing emotional and spiritual matters and I thought oh that looks great and I picked it up and I had a look at it and there was nothing in that pamphlet that to me addressed spiritual matters. And I was really disappointed. So you know that says to me that there's a great big gap in our service. We like to talk about holistic, that's a big buzz word but we don't quite get there. And in some ways I wonder if that's because we work from a very Western model and it would perhaps have things from other cultures that we can borrow and bring in that would enhance that, because the whole area of death can be so traumatic for people, you know, there are so many unknowns we don't know what's going to happen. It's easy for staff at hospice I think to go into default mode, the things that we're comfortable with, the things that we do well, but the spiritual stuff that I mentioned that's not in this pamphlet it sits out there, that's a little bit hard. So that doesn't often get addressed with these people. One of the difficulties that we find, as chaplains, I work with my husband, he is a minister, I do more visiting than what he does but, you know, we work as a team so if there's a man in here that I think might relate better to a man then my husband would come. We basically only visit those who are in and available and we, you know, while we are available to other people in the community they could say to one of the nurses that calls, you know, oh gosh I'd like to see a chaplain, they can jack it up, we'll go and visit at home, we're accessible in that way. We come from a Christian faith but are open to supporting our multi faith community, there is a growing Muslim community, we have seasonal workers from the Islands who are predominantly Christian but they offer cultural differences within their religious belief systems, there is a relatively strong Bah a'i group, there's a Buddhist group but, you know, we don't work with them from that point of view. We are comfortable being with people and working out what it is that they need, I do that by switching off from everything that has been going on around me, finding that interior silence in my mind, I wait before God in prayer that I will be guided to know what to do as I sit alongside a person in a time of need. I never presume or question, I'm not there to fix or sort, I am there to hold a space for spiritual or religious reflection or healing to occur if it is meant to. I help people to find that silent space to think or to just rest. Sometimes there is prayer, sometimes no room for words but an encouraging smile or holding a hand to make a connection, I know in this moment I have a connection with God as I feel His presence though my touch, I don't say that to the person I am with, it might not be their way of thinking but if I can use my connection with God to make a difference for them then that is my tool kit, Doctors can have their stethoscope, nurses their caring touch, our physio their walking frame and I have the silent support from God. But when you've got staff members who don't necessarily have any faith they're not thinking spirituality, in fact then they won't offer what might actually be really useful to a family in that time of need. It's not that we want all the doctors and nurses to become proficient at providing spiritual care but even if they can say ok that's not my area of interest, I don't care about that or, maybe there's a hole there I'm not providing a need that they have, ok I can see that need I'll ring the chaplain. And that doesn't happen enough.*

Glenda invites us to really think about the philosophy of palliative care when she is suggesting without spiritual care we are not providing the holistic care that our vision is centred upon. She highlights her ability to be with people and meet them where they are at irrespective of spiritual or religious synchronicity. She is part of the inter-professional team but colleagues do not always refer patients to her, as their own beliefs may be getting in the way of helping others. She also offers insights of how silence contributes to caregiving at the end of life by being with another person, silence can offer comfortable companionship; as silence deepens a sense of intimacy and connection occurs as described also in the research by Bassett, Bingley, and Brearley, (2018).

Silence may also enable a connection to self as told by Shaun

> *The crazy thing about this dying business is that it has made me a better person, I keep saying this but it's true, I've always tried to do my bit in life but I love a good time too eh, and I've sown a few wild oats I guess if ya get my meaning (…) now I'm stuck in this bed* [spinal cord compression has left him immobile] *I've had time to think and I can't fill the days as I used to and the nights are long (…) but this is the first time I have been in this quiet space, it's the first time I've turned inwards, being a bit of an 'out there bloke' but looking inwards I've found something in that quiet bit inside that shows me I've had plenty to be ok with, in fact I guess I could say proud of (…) my life had been ok.*

Moreno and Stanton (2013) reviewed 197 studies looking at the phenomenon of perceiving positive consequences and making meaning of the cancer experience (personal growth) with the aim of encouraging medical professionals to consider and respond to their concerns around meaning within palliative care. Shaun referred to his nurse validating this experience

> *She sat, quietly listening to me as I told her I had had this kinda realisation, I could see her taking it all in and a kinda look on her face that I wondered if she was going to say I was barking mad, cos she knew I had been a bit of a 'Jack the lad' but she said a lot of people experience that and wasn't it great. Ok so I'm not unique after all* [laughs] *I've learnt a lot, I can tell the kids this stuff, like I guess it's true ya never stop learning and to do that before you die . . .well it's never too late.*

Shaun's nurse was able to be fully present in this conversation. Schaffer and Norlander (2009) suggest that 'being with' or 'being present' is more than the physical proximity, it is the essence of nurse-patient relationship. The nurse needs to be attentive, accountable, sensitive, open and actively listening. Steinhauser, Alexander, Byock, George and Tulsky (2009) explored the important tasks people living with advanced cancer were concerned about. Their research revealed the importance of being able to say goodbye, attending to unfinished business, sharing time with family and friends and remembering personal accomplishments. The research further suggested that people want their health professionals to understand them as people, for who they are, not what they are (referring to diagnosis for example, ‘the man with prostate cancer’). Being connected on a human-to-human level is important at the end of life.

The *silent* and *inward looking opportunity* offered to Shaun allowed him to reflect on his life and to find meaning, acknowledged by the insightfulness of his nurse, sitting, listening, validating.

Carolyn also offered her experience:

> *Can you hear my ticking clock? My mother had it in her front room, there is something about the rhythm of it that gives me peace. Perhaps it’s knowing I might see her soon? In the still of the night it is comforting. I’ve had a good life, the usual ups and downs we all have but in the middle of the night when sleep leaves you, I quite like thinking about how I have found life and my place in it, the business of the day has gone and I’m left to my thoughts, its restful . . .yes restful. I have found that quiet place in my garden too. When you know you are going to die, I think it somehow shakes you up and you learn to live in a funny way. I notice how green the trees are, there are so many shades of green and my flowers have such clarity of colour, you know life is busy and you don’t stop to appreciate this, you should take note, appreciate it now, so you have more time with beauty. And feel the sun and hear the wind, you need to do this, make sure you find time for being still.*

Discovering the quiet stilling space in the night when sleep leaves her, changes Carolyn’s relationship with the world. She is also inviting me to consider “*you should take note”.* The busy day to day activities leave her in a quiet space, perhaps also the fading light leading her into darkness, reducing visible distractions as we look inwards, I consider being wrapped in silence negotiating dialogue with self and my world as I consider her lived experience of being in this space. She finds peace and connection with the ticking clock, her mother, nature, and I observe, a graceful presence as she has welcomed death into her understanding.

I return to my reflexive journal:

> I wonder how many times I have sat with someone not able to answer the big questions in life. What has my life been about, what was I put on this earth to do, where am I going next? I reconnect at some level with the inspirational book of Viktor Frankyl – ‘Man’s search for meaning’, which reminds me that finding meaning in our existence is the essence of being human. I cannot do it for another, it has to be lived out through deep reflection, I can be the catalyst for it to happen if it is meant to, by providing the right environment, by being the willing listener, being encouraging and affirming the experiences that are revealed to me. There is always the opportunity and possibility for meaning making, the creation and search for meaning even when time is short, as I have lived through in clinical practice witnessing this. I have had many teachers and gained therapeutic insights, building on my knowledge and understanding, aiming to assist the next person and their family in my care for a short, always intimate and privileged moment in time. Considering the humanities and some of our great writers on the topic gives another insight to the human existence and existential questions that are raised. Along with Viktor Frankyl’s writing, I recall Tolstoy’s book, ‘The death of Ivan Ilyich’ where he reveals the dying process and highlights the potential for redemption and growth right up until the moment of death. Perhaps at some level when we acknowledge our lives and find meaning in them we learn to accept death. Mitch Albom wrote about this in his book ‘Tuesdays with Morrie’ suggesting the truth is, once you learn how to die, you learn how to live.

Nurse (Sharon) finds the silent connection with self in the business of her work that gives her energy to continue her giving role:

> *For my own practice I think that ‘quiet being with’ time is an important touchstone because there are times in your practice you’re challenged and I do think you’ve got to be mindful, got to be prepared to go there for yourself, for instance there are some situations where while we are about being holistic, about supporting the total person and their family, you know there are times with physical symptom control or emotional or spiritual symptoms, it can be challenging and can be difficult. We need to develop an understanding that you can find peace and quiet*

> *in the middle of chaos so that you can be useful. Working in palliative care you know, it's been quite a journey in coming to understand and accept what is important for people. And I've found out they need me as a person as well as their nurse who can bring the medication and carry out caring tasks but in needing me* [Name] *I need to visit that quiet place inside to find the peace and energy to keep giving.*

Nurse (Helen) also experiences this by saying:

> *That kind of quiet place within, it is not the absence of noise that I am talking about, it can be very noisy all around me but you can switch off to that and tune into the present moment. It has a particular quality of connection to it I guess. I can be fully present even if silent.*

These experiences resonate with my own discovery that being comfortably in silent stillness within self, enables me to be fully with another. Sharon and Helen find silent connection has a therapeutic benefit for the person in their care, they are being respectfully listened to or if they themselves are silent, then silent carer (in this case Sharon and Helen) the silent connected relationship is affirming that being in silence is still communicating. We cannot be in this space without calming and quieting our minds and focusing our intention so we need to find that peace amidst the chaos as Sharon mentioned. I turn to my reflexive journal:

> I am reminded of the teachings from Frank Ostaseski, from the Zen Hospice Project in San Francisco. He talked about a woman struggling for breath as she was dying from respiratory disease and could not relax. All forms of medication and complementary practices had been tried, with no relief for her. As he sat with her, quietly watching what was happening he noticed a moment of peace between the inhale and exhale of her breathing, perhaps a nanosecond but still a moment of peace. He then drew her attention to it and invited her to concentrate on that moment and find that brief experience of being suspended in the void of nothing which offers a break from the continual suffering. She was able to do that with his guidance and she died peacefully later that night.

The Buddhist precept of finding peace in the middle of things, was helpful to her, and also supports the offered narratives and resonates with my own clinical practice.

Intuitive Silence and Gratitude

All health care professionals spoke of or gave a narrative demonstrating how they trusted intuition as being a key principle they worked with. This comes from being very experienced in their practice and having developed their clinical judgement using this instinctual process. I have included Jane's exemplar to illustrate this way of knowing. She demonstrates that intuition and silence are helpful strategies in supporting the dying.

> *Reading Jean Watson and Kübler-Ross' writing believing you could transmit thoughts to people and I can remember sitting with a woman one day, she was dying and she lived on her own, she was on her own this day and she was very unwell, she was dying and was obviously going to die today within a very short time, and I kept thinking, whether I should stay here or whether I should go, I haven't got a clue in what I think is right for this woman, but she obviously she was somebody who was quite comfortable on her own so, I thought that I would try this theory, I'll actually stay here. I was quietly saying to myself and I was saying to her, if you would like company today, I would stay here for half an hour and you could die in that time. But if you'd like to be on your own I'll go and you can die on your own . . . she did die after I left. I mean there was a real sense that this why I think back and know that there is some [way of transmitting thought] communication. . . for me the learning was, if we trust one another as human beings and as individuals and it's an open space to know that it's safe to choose the time that's right for you, because there is a time that is right for everybody.*

Intuition, as described by Benner and Tanner (1987), is understanding without rationale. In this intuitive moment of acting, a connection was made between Jane and her patient. Connection implies an intentional act to create a bond or special relationship with another person, acknowledging and binding them in a special way. Montgomery (1992) and Clayton, Murray, Horner, and Greene (1991), describe connection as presencing, attending, affiliating and empowering the other.

Marks-Maran and Rose (1997) support the concern that intuition in nursing has been undervalued and frequently ignored. They suggest that the current move towards evidence-based practice can only continue this trend. SchÖn (1991) refers to reflection in action, based on knowing in action. It is the tacit 'intuitive moment' where the nurse knows the right or wrong thing to do, which leads her/him to change their course of action. Jane wasn't sure how to read the situation for this woman, both options were appropriate to consider, but by reflection in action, Jane enables the right moment to occur by offering to stay if she wanted company in her dying but then leaving to allow her the opportunity to die the way she had lived – on her own. Kaiser and Kaiser-Carlson (1999) suggest that intuition is never wrong, but it can be overpowered by emotions. Jane could have felt emotionally torn at leaving this woman on her own but she also acknowledged that having been comfortably on her own for most of her life, she intuitively understood that to die on her own was realistically appropriate. It remains a challenge to distil the truth and make the best possible decision based on what is thought to be so.

> *If you're actually with somebody when they're dying it's like two common souls, yeah. . you have the privilege of actually being with another human being (…) that's what it is, that sort of sense of intuitive knowing and sharing at a different level and you do that with people (…) I think that's the really special part of it. I have been lucky enough to be in a position where I have been able to understand life in more depth than most of us have the opportunity to do and I think, I suppose, it is like that thing where you sort of see things on two levels, I mean, birth and death are the ultimate connections aren't they and it's like I have had the privilege of being an intimate part of many people's deaths, it is a privilege it's, it's allowed me to see what's important.* (Jane)

Jane's warm and caring tone of voice and her reflective persona was clearly showing me during this moment in the interview that her practice has had a profound influence on her life. Palliative care has had many special moments of connection on a deep and intimate human-to-human level. Benner and Wrubel (1989) refer to connecting as a fusing of thoughts, feeling and actions, integrating knowing and being. Connection leads to a transpersonal feeling with bonding between caregiver and care receiver at the soul level (Leners, 1992). I was learning from Jane's story and way of being, that her caring practice incorporates a consistent value system which recognizes each individual, giving presence, and coming together with compassionate, therapeutic care. This is not an isolated moment but rather constitutes a way of being and doing in palliative care.

At the end of our interview time, Jane articulates the process as:

> *it's like it's put a part of my . . . an incredibly important part of my life in perspective, which is fantastic…*

Phenomenological research provides health care professionals with insight into the personal experiences of illness and dying. van Manen (1990) refers to hermeneutic phenomenology as a "critical philosophy for action" (p. 154). He suggests, "hermeneutic phenomenological reflection deepens thought and therefore radicalises thinking and the acting that flows from it" (p. 154). This research process for Jane allowed for some time of thoughtfulness, which in turn has the potential to be a learning moment for personal and professional reflection and critique of practice.

A bereaved family offered their exemplar highlighting intuition and gratitude for it:

> [GP] *and* [District Nurse] *just kinda knew when we needed them, I mean they came on their scheduled visits but at times they just seemed to know, like they had a kinda sixth sense if that makes sense, and just arrived when we needed them.* (a knowing laugh and eye contact between sister and her two brothers as they decided to tell a story). *Yea that night, remember? Dad had wet the bed, really flooded it and we woke up as Mum needed our help to deal with it, it was nearly 1am and in the middle of this* [GP] *tips up at the door asking if everything was alright, can you believe that? (…) she had been to a ball as it turned out and was on her way home which goes past our place and saw the house in a blaze of lights and was concerned. That was really going beyond the call of duty don't ya think? Dad loved it cos she was all dressed up and her hair was all pinned up, looking really glam, lovely long dress, lots of bling and Dad thought he must be dead already cos he was looking at an Angel, said he was quite surprised he had ended up in heaven, odds were on he was hell bound he thought. (…) we made a cuppa tea, Dad wanted to know about her night out, she said she would tell all if we didn't mind if she kicked her shoes off, her feet were killing her, and she plonked herself in the chair beside the bed, hitched up her dress and threw her feet up on the bed in relief. Dad loved it, said he bet they didn't teach her to do that at Med School. But the point was she treated us as normal people, there wasn't the hierarchy of Doctor patient stuff, we really, really, really, appreciated that, she had a way of knowing just how we needed to be related to, don't get us wrong, we really respected her and didn't take anything for granted, she was a really good Doctor for all of us, knew what to do for Dad and Mum (…)* [brother takes over talking from is sister] *she helped me too, I was struggling with what I saw happening for the 'olds', I couldn't really cope so avoided coming as much as I should have (…) but one day when I was there* [GP] *tips ups, I didn't say anything and after she had seen Dad, she found me out on the back porch and sat down on the ground and talked out to the garden* [laughs] *she must have known if she had eyeballed me I would have up and left, crafty uh? She said, I can tell you are finding this tough, you seem to be the one in the family who likes order and structure, how did she know that? It's true, and this was not going to plan in a logical way I guess. I needed to know the process and a timeline and she seemed to have the knack of validating my way of thinking which was different to* [sister and other brother] *she explained things in a way that helped me and I started to visit more which helped Mum and the others, ha ha she had this way of just knowing, is that intuition, insight? I don't know but it's really clever, helps.*

Patients and families often express gratitude for the care received towards the end of life and in this exemplar where the family refer to the intuitive knowing from their GP,

they are grateful for on many levels and it is helpful to them. McCullough, Kilpatrick, Emmons, and Larson (2001) refer to gratitude as a reaction to something which is appreciated. It is an interpersonal interaction, an emotion, in which the person reacts to the help received, which is considered valuable and altruistically offered (Lane & Anderson, 1976; McCullough et al., 2001; Tesser, Gatewood, & Driver, 1968).
Families are often grateful for the end of life care that maintains dignity and respects the dying as a person. It also involves, where possible, supporting them to die peacefully, with minimum suffering. Within the context of palliative care, a patient's death is often followed by expressions of gratitude from relatives. Acknowledging that it is common for patients and families to express gratitude in the context of care, Aparicio, Centeno, Robinson, & Arantzamendi (2019) undertook a scoping review of the literature with a focus on expressions of gratitude from patients and families to health professionals including their meaning and impact. They highlighted that patients and their families were grateful for the health professional’s technical skills but above all, for human skills, their physical presence, engagement and good sense of humour. This was lived out in the above narrative:

> *the point was she treated us as normal people, there wasn’t the hierarchy of Doctor patient stuff, we really, really, really, appreciated that, she had a way of knowing just how we needed to be related to*

The cup of tea and feet up on the bed, enjoyed as humour as they noted:

> *Dad loved it, said he bet they didn’t teach her to do that at Med School.*

This may be construed as unprofessional but clearly the GP knew the family well, had been involved in their care for a long time and intuitively, read the environment and relaxed into the moment, quite possibly leading the family to relax as well after their late night burden of laundry and subconscious meaning of what was ahead.

In regards to valued human competencies, Aparicio et al. (2019) highlighted communication skills such as giving necessary information, explaining doubts, time spent and concern for individuals at a vulnerable moment were also a subject for gratitude. The son, offering his thoughts in the above narrative certainly benefited by the GP’s ability to see that he was on the outside of his family’s way of being and she validated his thoughts and communicated in a helpful way that he was grateful for.

The patients and family members in this story were grateful for what might be perceived as ‘everyday’ care and, also, for care that might be viewed as going above and beyond what was expected. Hallmarks of care that generated gratitude included care that met a particular need, was offered at a vulnerable moment, and in a way that demonstrated genuine concern and connection.

Being Silent for others

Not knowing what to say to someone who has a life limiting diagnosis or who is dying is a problem for many. Professionals, as well as family members, can struggle with what to say and how to say it. We are often at a loss for words, forced into a silent world for fear of causing offence, hurt, or upset or simply feeling awkward. This is also true for the person who is dying, not wanting to upset family and thus a conspiracy of silence may dominate and is hard to break. Lemus, Carreño, and Arias-Rojas (2019) highlight that the conspiracy of silence in palliative care has a negative impact on patients and caregivers, and encourage health professionals to be attentive to identifying the phenomenon and be prepared to intervene. Participants in this research mentioned protecting their family and friends by not talking about their illness trajectories too often as they disliked seeing them upset and didn’t want to cause undue stress or burden them with their thoughts as Barry offers:

> *We do talk but not lots really, we both know the reality of what’s ahead of us but you just know and keep it to yourself. It’s easier that way. When* [Nurse] *comes I can ask her anything or mull over things with her without upsetting her whereas the wife, she tries not to cry but she does and it breaks my heart.*

And a daughter talked about how the GP visiting became the ‘bridge’ to enable open conversation with her mother:

> *I could see mum deteriorating before my eyes and there was so much I needed to know and so much I wanted to tell her but I didn’t know how without us both being emotional wrecks. (…) mum’s belief system is a challenge you see, she believes strongly that if you talk about illness you invite it to become much worse. It was hell getting her seen by the doctors and getting a diagnosis because visiting hospitals makes you worse. She believes that prayer alone heals. Great eh? Look at her now, is this healing? Anyway anyway anyway (…) she was mute about what was happening and I was too when it came to talking with her until the GP called me into the bedroom on one of his visits and said “do you know what your mother and I have been talking about?” And from that simple question,*

> *he connected us, it was like he was a bridge over this troubled water of not being able to talk, he said he believed we were thinking and feeling very similar things and yes it was hard and yes there would be tears and fears but fun times too. It was a relief to be honest, but we needed the bridge to get us there.*

On a visit to one service where I had scheduled interviews for this research, I was invited into the Art Therapy session and introduced to the group as a whole. Although those present were not formally interviewed, they were eager to tell me about attending this group. I captured the essence of my time with them in my field journal:

> The gift of beaded angels. A group of 12 have met today in the Art Therapy session, 2 inpatients of the Hospice and 10 have come in from home, a safe refuge for time out. They are very animated and keen to show me their work and what having this opportunity means to them. One man is completing a painting for his son, probably the last one he will do he informs me. I acknowledge his talents with envy as I inform him I missed out on all the artistic genes but can admire the talents of others, he smiles. What leads you to believe this will be the last landscape I ask, and he offers his story and gives a brief laugh "you are just like the rest of them here" he offers. What he is saying is, that coming to these sessions with the Art therapist and volunteers who support the programme, people talk about their illness if they want to, or are free not to if they don't. Nobody minds either way, but it is an easy flow of conversation, attendees are in different stages of their illness but it unites them and it forms, by default, a support network if they need it. No one is afraid of talking about dying, the conversations don't linger as they are keen to get on with living. Four women invite me to join them they are making angels out of beads, their experiences are the same, they find support from each other, it is a nurturing environment to have fun, to laugh, to cry, to celebrate being well for now and mourn the loss of friends they have met but have died during the time they have been coming, again they are telling the human story, the reality of life is often in the shadows of our everyday lives. They thank me for listening, they want others to know the hospice and its services are great and people should not be afraid to come, but all admit they were afraid in the beginning as

> they had little idea what went on down this long driveway. They gift me two beaded angels to guide me, to look after me, to symbolise we are in this together they say, indeed, we will all walk this path. The angel, is frequently seen as symbolism of death and dying, of religion and spirituality and literally means messenger. I am once again invited to reflect on the messages they have given me today.

Silent meaning of symbolic language

“If people would listen more to their own intuitive spiritual quadrant…they would begin to comprehend the beautiful symbolic language that dying patients use when they try to convey to us their needs, their knowledge and their awareness” (Kübler-Ross 1991, p. 60). The health care professionals commented on the use of symbolic language used by many in their dying time and how when busy, they often missed picking up on it but noted how loaded with messages these stories are. At times they assisted families in the translations of the meanings and signposted this as a form of communication most often experienced when death was imminent. We are asked to ‘listen’ rather than simply ‘hear’. Examples offered in a variety of participants transcripts were:

> Are my shoes at the door?
> Tell me what the tides are doing
> I don’t want to miss the boat
> It’s time to get in line
> It’s time to pack my bags
> My cupboards are tidy, the housework is done
> I’m off to the yard, the drafters are coming
> Saddle up the horse

Often these comments, or stories that surround them, can seem like hallucinations or ramblings of a dying mind, or attributed to medication or electrolyte imbalances and at times this is true, as some forms of dementia or mental illness may predispose someone to this way of communicating, but metaphorical language does not need to be pathologised, but rather listened to. Kraybill (2005) invites us to examine the language in a symbolic sense to become more aware of specific desires or needs of the patients, as we gain greater knowledge of what the dying experience feels like. Sanders (2007) points out that symbolic communication can be a dramatically effective tool to share unseen knowledge. I would add to this by suggesting it also allows us to hear their reality in the silence of everyday language as symbolic language emerges.

This form of communication is best understood in the context of the individual's life. For example *"I'm off to the yard, the drafters are coming"* or *"Saddle up the horse"* has origins in a rural settling. The metaphor of travel is commonly used as a signal that the groundwork for death is being formed within, suggesting a theme of going somewhere as a logical way of expressing their imminent change of location (Sanders 2007, p. 27).

I note one of my many experiences of communicating with symbolic language in my reflexive journal.

> D, a pioneering woman, loving the outdoors, scaled mountains, kayaked gnarly rivers, tramped remote passes, flew light aircraft and lived a solitary life. She invited me in to learn about dying through the metaphor of skiing, a sport I love! As I put my head around her bedroom door, she gives me the weather forecast. "It's a whiteout" means no going up the mountain today, so we don't talk about her illness or dying. "Its clear visibility and I'll be ready to as soon as you are "an invitation to sort my workload to make time for her. We talk. She offers that we can go up the mountain together, share the ride, share the ski tow, but she needs to come down the slope on her own and how she gets down depends on the snow conditions. Fresh deep powder a joy to traverse, icy hard, your edges need to be sharp and a higher chance of falling, moguls bumpy, can be fun, but can be exhausting. She is teaching me about her journey into the unknown sharing the highs and lows as she works her way through making sense of it all. All by symbolic language, no dying mind or drug induced haze, but with clarity and composure. She then tempts me by saying, "if you really want to learn about this journey, you need to learn how to fly". She was the catalyst for me to explore this idea, and I acted on her invitation. I had got to the cross country part of the training before she died. Her sense of humour and opportunity to tease me was offered on a plate as I told her of being caught in a nor' west down draft over the Rakaia Gorge, when my stomach was left near the clouds as we

> dropped what seems like miles at the time but in reality was probably very little . . . my own near death experience. She loved it and said “now we can really talk”.

If we dismiss the symbolic language or do not find the time to reflect or decipher these messages, we lose opportunities to experience the very essence of the journey, as this lived experience acts as an invaluable teacher promoting greater sensitivity and communication with the dying. I recall talking to D during one of her admissions to the Hospice service after I had skied the Tasman Glacier at Mt Cook. She asked if I had straddled both sides of the National park while up there. Tuned into her symbolic language I became aware of the notion of having one aspect of life looking back on what has been experienced and achieved and the other looking forward to where they are going, the dying have the opportunity the use the duality of the experience for review and discovery. And we as silent observers, learn.

Review

To explore the concept of silence in the lived experience of those giving and receiving palliative care drew my attention to the themes of connection, suffering, intuition, gratitude, unspoken and symbolic language, raising my awareness to the often overlooked yet vital essence of caring. The extent to which the phenomenon of silence has been revealed will be determined by the extent the voices of these participants have resonated with the reader, enabling some silent reflection, honouring the gift of these experiences as they have been lived through by each person. By sharing these stories, they may be a catalyst for others to voice their practice wisdoms and assist in articulating the essence of human-to-human silent connection between health professionals and people who are dying. The phenomenological methodology has allowed for the authentic experience of the givers and receivers of palliative care to prevail, as each narrative is a paradigmatic case in its own right and we begin to see what it means to live these experiences.

There are multiple voices of silence. Silence offers companionship and connection in suffering, it enables us to be present in an authentic space. Shared silence enables both parties to emerge changed in our understanding. It invites us to attend, to listen, to validate when there are no answers but we stay together in that difficult space, honouring the experience. Time to ourselves to reflect on life, to process, for spiritual connection, restoration, and to find peace.

This chapter utilised the phenomenological methodology of data analysis informed by van Manen and we hear the voice of the participants along with entries from my reflexive journals to reveal the voices of silence. The importance of warmup stories was offered as a way to develop and engage in a trusting and respectful relationship with participants. The chapter was written as hermeneutic text with literature utilised to explore, support, enlighten and clarify meaning and experience rather than used to expand on knowledge. The following chapter offers an additional lens on the importance of silence, as an unintentional consequence of undertaking this research.

Chapter 6 Unintended Direction

The greatness of a community is most accurately measured by the compassionate actions of its members. -Coretta Scott King

The previous analysis chapter revealed the essence of silence offered by the participants, both givers and receivers of palliative care services. The hermeneutic circle of engaging with the data as a whole and the parts that make the whole, required moments of deep reflection and journaling for clarity of insights offered. This chapter reveals the unintended consequences of the research, offering an additional lens through which to explore the role of silence.

Keeping of a reflective journal throughout the phenomenological research journey is encouraged, as noted in Chapter 3. It assisted with a deepened self-awareness to remaining open to the participants' experiences described at the interview. It enabled my pre-understandings to be explored in order to understand the way in which one may influence the interpretation of the narrative. It enabled a recording of the context of the interview and observations that could not be captured on the audiotape. It also provided an opportunity to explore my own lived experience of the research journey, to walk alongside my participants as they invited me into their world for a moment of time, and to capture my experiences along the way. According to Jasper (2005), reflective journal writing allows researchers to own centrality of their research process, which contributes to the legitimacy of the knowledge claims. Therefore, my diaries became a key component of data gathering, separate from the narratives collected from research participants, but placing them alongside provided an additional level of revealing, exploring and considering emergent insights. Journal excerpts were utilised in the previous chapter to explore the essence of silence being led by the participant's voice. In this chapter I re-enter the hermeneutic circle of analyses to move between the part (being the reflexive journal) and whole (giving additional voice to silence) so that understanding becomes more complete.

The hermeneutic circle and process of interpretation leads to a fusion of horizons as understanding takes place (Gadamer, 2004). In the fusion of horizons there is opportunity to "extend meaning from what is directly given" (Gadamer, 2004, p. 536).

An opportunity to discover something more; a new perspective and shared understanding of the subject matter (Vessey, 2009). Phenomenologically, these matters are the lived meaning that dwells in experience and the lifeworld, made manifest through the mode of given-ness (Husserl, 1970).

In the shadows of silence

Uncovering the essence of silence in the interviews with both the givers and receivers of palliative care services required reflective moments for sitting with the nuances of this important phenomenon. These reflective actions raised my interest in what was *not* being said. The benefits of phenomenological research may be found in the reform of understanding, in what its serious pursuit "does to us" (Burch, 1989, p. 204). This effect is one we feel, and it encourages us in the possibility of more thoughtful action. As I was writing, and rewriting, to understand and reveal the phenomenological description of silence, then engaging through reflection on the process utilising my reflexive diaries, I noticed an increasing moral tussle and I asked myself, what is not being said that may be important to understand? What is in the shadow of silence?

The moral dimension of nursing is well known (Bishop, 1996; Bishop & Scudder, 1990, 1991; Watson, 1985; Benner & Wrubel, 1989). Well known and written about because nursing is a relational practice, the meaning that is generated in the relationship of care, strongly influences the outcome of care and influences our decisions and behaviours. Ethical competences support clinical, relational, and technical competences because the values and ethical principles of the professionals play significant roles in clinical decision making (Jormsri, Kunaviktikui, Ketefian and Chaowalit, 2005).

There is a healing power to caring in the palliative care context, one which I have personally experienced in practice as being more helpful than the evidence-based protocols and procedures promoted in today's health care environments. However, our education, training and experiences sit firmly behind the healing power of caring with logical reasoning and problem-solving skills. This is helpful, as depending on the depth of relationship with those in our care, emotional decision making can come to the fore (Stein, 1989). Reflective practice that accompanies clinical decisions of nurses includes the moral aspects of care (Bishop & Scudder, 1990; Benner, 1994; Hargreaves, 1997; Fairchild, 2010; Park, 2012). As Benner, Hughes and Sutphen (2008) state:

> The development of the healthcare professional's ability to reflect critically depends on what she has learnt to pay attention to: to search for salience means to gain the ability to see and understand what is relevant in a given situation and the capacity to respond to it. The sense of the salience of a healthcare professional in any situation of care depends on her past experiences and current scientific evidence. Critical reflection is a healthcare professional's crucial competence; however, it is not the only logical reasoning skill or clinical logic required. The ability to think critically uses reflection, induction, deduction, analysis, risk-taking and evaluation of the data and information guiding the decision-making process. (p. 89)

Palliative care also invites ‘soul searching’ as we listen to the stories of those in our care. When we engage with quiet respect, attention, discretion and creativity (Charon, 2006) we hear the questions that are often unanswerable, and soul searching unfolds. Scott (1998) refers to this as moral imagination and Nussbaum (1997) considers it as narrative imagination, suggesting narrative imagination is an essential capability that one must have in order to cultivate humanity in today’s world: without the ability to think creatively about events and real things deriving from a given situation, it is not possible to feel empathy and compassion for others (pp. 74-75).

Phenomenology offers a way to think about our practice and the recipients of our care. In the role of researcher, I engaged with the opportunity to restructure my reflections. I reconsidered the participants who were in my care during the interviews, and become very attentive to their individual and collective experiences of palliative care, to reveal new understandings. In the essentially positive and engaging stories that revealed the beauty of silence, I wondered about the shadow side. Heidegger (1971/2001), in talking of the beauty of things, suggests beauty as a meaningful presence, which shows traces of truth. However, at times the truth also obscures itself from us.

It was interesting to note in the transcripts that there was no mention of the physical pain of dying, yet the truth is that most people associate rightly or wrongly with pain as part of the final journey in life. Managing physical symptoms is a skill set that health professionals working in palliative care are reasonably proficient at. In New Zealand we are fortunate to have a range of medications that are beneficial for most symptoms, as it is medication we are reliant on in end-of-life care. The disease process is not able to be arrested at this time and therefore management of troubling physical symptoms by medication is essential and supported by a range of complementary practices such as relaxation, massage, visual imagery, and music therapy, to name a few. Dying can have its challenges depending on disease processes. Symptoms can be difficult to manage, wounds can be distressing and odorous, urinary and faecal incontinence is undignified. Suffering can occur if the physical pain is ignored or considered uncontrollable, or when a person's emotional pain is dismissed as inevitable, or misunderstood. As Payne (2013) notes, death is often a lot less serene than one might think. Death can be like life – a bit messy and awkward – some people die as they have lived – at odds with the world. The health professional participants didn't dwell on the physical symptom challenges of dying, or the messy awkward side of dying, nor did the consumers of the service note them with any relevance. This could be as a result of the confidence and competence of practitioners in assessing and managing such issues and in recognition of the range of medications available in New Zealand to successfully manage distressing physical symptoms.

> *Being able to prescribe a range of helpful medication is great, I have worked* [overseas] *where this is not possible and people are dying in abject pain, it is good that this doesn't happen here.* (Amanda)

This position was reinforced by comments made at the beginning of the interviews in the warm up stories from the health professional perspective such as:

> *I know what it is about* [philosophy of palliative care] *but you can't do it all, we are time poor and just have to stick to sorting physical symptoms* (Vicki).

> *It's a wonderful idealistic aim but in the current fast pace of end-of-life care, unrealistic (. . .) If we had a full complement of allied health members in our team, we might stand a better chance of achieving it but you can only do what you can do.* (Margot)

> *We don’t provide holistic care if we are being truly honest, we have become a symptom management unit.* (Meg)
>
> *The way our service runs, we have to meet management and contractual requirements rather than meet the needs of the patients and families.* (Patricia)

The holistic focus of the philosophy of palliative care appears at some level to be missing in the care they are offering, recognised in the above narratives but not able to be incorporated, and I also note a field journal entry:

> Today I had my third experience of interviewing a health professional who offered comment on what I believe, they thought, I would want to hear. A curious moment when he said “now turn off that machine (referring to the tape recorder used for the interviews) and I’ll tell you what I really think if you would like that?” I listen with a heavy heart as I hear the struggles of what as clinicians, they would like to have the freedom to do in practice but feel the system is not supportive. I hear the excruciating moral challenge wanting to sit on a bed, to fully engage with people on an intimate level. Yes, as their health professional but more – on a human-to-human level, to put the art back into the science of medicine but time, expectations, pressures of needing to meet targets, following pathways, protocols, policies, procedures to meet contractual obligations and organisational expectations form a barrier. They reveal a sense of being limited to doing what is doable, articulated with dispirited voice and body language . . . I feel the heaviness, the burden, and tiredness and ask how do we go forward?

Silenced by the system

I applied the notion of the ‘listening gaze’ to the transcripts and re-listened to the voices of the health professional participants and considered what is not being said that is important. The participants highlighted the phenomenon of silence in practice, wanting to push aside the concentration on the physical symptom management that time constraints saw them focussing on. They acknowledged this as important, but this did not replace the intimate and necessary moments of silent reflection and connection with those they serve, to ensure they get to the heart of the issue important to each person.

The listening gaze is a phenomenological stance used by Madjar and Walton (1999). They suggest the listening gaze is not just a looking gaze but rather an openness or attitude to others, it is being attuned to the concerns of people, it is learned through practice and critical and thoughtful reflection. The phenomenological gaze tends to focus on the ordinary but can lead to the understanding of what is extraordinary. Munhall (1994) suggests:

> It is the taken-for-grantedness, the sailing though life without reflection, the dazed going-through-the-motions learned from whatever context that give way too often to the meaninglessness and alienation so characteristic of our situated context in modern age. Phenomenology, as a way of being, takes us from this dazed perspective to a gazed perspective where we give, reflect, and attempt to understand the 'whatness' of everyday life. (p. 4)

Munhall uses the term 'gazed perspective' in relation to the phenomenological way of being in the world, in the same way we often say "I see" when we mean 'I understand'. Van Manen (1990) also uses the metaphor of vision when he offers:

> Making something of the text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure–grasping and formulating a thematic understanding is not a rule bound process but a free act of 'seeing' meaning. (p. 79)

By pausing and reconsidering the untold stories and considering the essence of the listening gaze to see what is happening, I further understand the phenomenon. I see what is presented to me by the health professional participants in the untold story, in an attempt to find out what lies underneath, a sense of being silenced by the system and needing to reengage in the essence of holistic practice. As Birkerts (1994, p. 74) points out, we are often embarrassed by terms such as 'truth, meaning, soul, destiny' but we also hunger for more soul in our work, and we feel better when we are in touch with the depth of it. When we cannot practice according to our values, or moral complexity does not lead to solutions, moral distress can occur. Macleod (2011) warns that losing control of workload and professional autonomy and being challenged by managerial interference are the most irritating and destructive aspects of the modern consultant's job and are stressors more likely to lead to burnout than clinical issues or demands. The palliative care philosophy is also adding to the burden of care (noted by narratives above) by being so all encompassing that it raises the question of how realistic it is. This will be explored further in the next chapter.

The silenced community

An unintended consequence of undertaking this research revealed insights from a community perspective. The general community were not part of the research but were noted in my reflexive field journal. When applying the phenomenological lens of the 'listening gaze', as I was dipping in and out of my journal, the notion of a silenced community arose that may offer a way forward in end-of-life care. I share the following journal entries for reflective consideration worthy of further research.

Death café

> I note the time, I do not want to arrive at my next interview at lunchtime, I notice a café I have passed a few miles back and decide to return there and wait a while. A table of retired lunchtime diners turn and look at me as I take a seat. It is a small town and they sum up quickly that I am not a local. I know the look from my own rural upbringing. "haven't you got any friends today?" We laugh, and they invite me to join them wanting to know what brings me to the region. I cautiously reply "I'm talking with people to find out how they care for people who are unwell, very unwell, maybe in their final days of living". I'm caught by my own use of language, intrigued that I didn't use dying or death as I answered their question when I am a strong believer of not using euphemisms and wanting honesty and simple language to assist in bringing death and dying out into the open, to be normalised as part of life. In this instance I am not wanting to dampen their light hearted social gathering by talking about a sadder aspect of life, I am the cautious intruder in this instance. "are you a journalist?" they ask, no I am a nurse, I reply, and reveal my background. Suddenly their stories and experiences are offered and they tell me about how small communities are better at looking after one another but that they used to do it better than they do now. The change they put down to the Privacy Act, they point their finger at me suggesting "it is you people we blame, you don't let us in any more, you work in

> secret". I am momentarily rescued by stubby shorts and safety boots walking past, a stock truck driver has parked up outside and come in to get lunch, "Gez you guys have good lunchtime conversations – not! You must have guessed I'm taking these lambs to the works" He is invited to join us while his coffee is being made. He agrees, his Aunt died recently and his story was offered. In essence they were collectively suggesting the (Privacy Act 2020) was a stumbling block, they understood not everything in life needed to be in the public domain but when it comes to caring for the dying, they believe it is a community event, they are there to rally around, providing support in whatever way it is needed, they talked about dropping off firewood, leaving meals at the door, helping out with children or the elderly, assisting with farm work, lawn mowing, fetching things from town, calling in to see what was needed or delivering a bit of community news. The good neighbour idea, but due to the rurality of the region, weeks can go by without seeing many people and they worry families could be 'in strife' without help. The district nurse used to let someone know that there was a concern, not in detail, but as a 'tipoff' so they would rally around but now that has gone. "We could do more to help if you people let us in".

The final comment, "We could do more to help if you people let us in" lingers still in my mind, along with the realisation that in this encounter - an impromptu death café conversation took place that was useful to both parties. They offered me their thoughts to consider, and in turn used my experience of caring for the dying to ask questions they had wondered about such as:

> How long can people live without eating and drinking?
> Why do some people make gurgling sounds when dying?
> Why do some deaths have to be referred to the coroner?
> How do you help people who don't appear to be accepting of their illness?
> Do you have to use a funeral director?

Death Cafés are a relatively new phenomenon, initiated in 2004 by Bernard Crettaz in Switzerland, which he called a Café Mortel. He wrote a book of his experiences, which was reviewed in *The Independent* November 2010 (Guinness, 2010). This article caught the attention of Jon Underwood, a web designer who was working on a death related website. Utilising Crettaz's model for inspiration and co-hosted with his mother and psychotherapist Sue Barsky Reid, a death café was hosted in 2011 (Underwood, 2011). He also created his website www.deathcafe.com posting after his first death café experience:

> We had our first pop-up Death Cafe yesterday. It was a powerful and moving experience. It was attended by a diverse group including a grief specialist Kristie West, a Buddhist nun, a management consultant and a council strategist. It was expertly facilitated by Sue Barsky Reid, a qualified psychotherapist. We are energized by this and are planning more.

Since then the Death Café movement has spread internationally. It is a place for informal gathering of people over tea and cake, and creates a space for people to have conversations. It does not purport to be a place for education, counselling or bereavement support but rather a place where it is comfortable to be able to talk about what is on people's minds around death and dying and is considered to be very helpful (Miles & Corr, 2017). What unfolded for me that day was an impromptu experience and appreciation for how death cafes may serve the community.

The Bakery

On another occasion, in an urban setting I note in my reflexive journal a story captured by the bakery owner when I call in after interviews at the hospice nearby:

> I go in at 4 in the morning and start preparing for the day ahead. There was a knock on the door, two men outside in the damp drizzling early morning asked if they could come in and shelter for a while. They had been in the hospice, sitting at the bedside for the past few nights with someone they loved and needed to take a break. The light rain had cut their walk short but they did not feel ready to return. I said, come on in. I can turn the coffee machine on if you like? There is a table in the corner – stay as long as you like – I won't interfere, but you can rest for a while and if there is anything you need – just shout out. They came for the next two mornings and then no more. Several weeks later they called in. Their relative had died but they thanked me for offering refuge to them, the

> hospice, you know they do good work there – but they can't do it all, they should let others help, it makes us all feel good. Like the time when one of my regulars just stopped coming, I went around to see him, I knew where he lived and took the loaf he always bought. He said he had had a bit of bad news and was not going to live for long. We talked about what I could do to help – he said I could if I knew someone with a Lamborghini as he always fancied a ride in one and would have to do that soon – it was on his bucket list. Well I did know someone – he was also a customer; I didn't know him well but I was prepared to ask. He was very happy to help out. They had a great time, and somewhere down a quiet semi-rural road, the guy who owned the car, pulled over and handed the keys to the sick man. I reckon he must have died real happy . . . . don't they fill you up with drugs like morphine when you are that sick? I didn't like to say that to the Lambo owner – what would have happened if the cops had pulled them over and he is high on that stuff behind the wheel of a super car? Some things don't bear thinking about, but the Lambo owner was real pleased to be able to do something nice and I felt pleased I could make it happen for them both.

These two journal entries along with the restaurant story mentioned on page 6 were not part of the formal research process but they do offer insights into the reality of researcher experience. If we are open to them, they offer reflexive moments that may add to the richness of the whole. They can be considered 'unintended consequences' of undertaking research. 'Unintended consequences' arises from the term 'unanticipated consequences' coined by Robert Merton (1936). This conflation suggests unintended can also be unanticipated consequences that may obscure an interesting and real aspect of a phenomenon (de Zwart, 2015).

Re-entering the hermeneutic circle to situate my research experience as captured in my reflexive journals extended the notion of silence revealing the shadow side of a silenced health care system and community which will be further explored in the following chapter.

Chapter 7 Discussion

To listen deeply

To another is to care

To choose

To be empty of self

That true communication may take place.

Who’s empty? Few only.

To listen profoundly

Is to be still inside

That you may hear

The flicker of an eyelid

Or a heart

About to open

Like a flower

In silence.

The greatest revelation is stillness. -Lao – Tse

Chapters 5 and 6 uncovered the lived experience of silence from the perspective of those receiving and giving end-of-life care. This chapter does not provide a conclusion for palliative care practice or conclude fully on the research aim. Phenomenology does not provide a final word but rather a message from the text; it is a “poetising project” (van Manen, 1990). Van Manen suggests to summarize a poem in order to present the result would destroy the result because the poem itself is the result. The poem is the thing (p. 13). Therefore, I cannot separate the results from the way in which they were obtained. That is, honouring the journey the participants took me on as this research unfolded. The findings were from their lived experience in the palliative community of care. By examining an experience as it is lived, new appreciations can develop to inform or re-orientate our understandings of silence. The intention of this chapter is to weave the stories of lived experience together, shifting from the depths of understanding silence to a broader philosophical discussion for palliative care and the community at large, offering the concept of a Compassionate City for consideration to incorporate the ideals into strategic frameworks for the way forward. Further exploration of the literature will be utilised to illustrate the way the research has shifted and reawakened my understanding of silence, and the implications for people giving and receiving palliative care.

The sounds of Silence

The moments of often personal and intimate connections with people receiving and delivering palliative care during this study, revealed through their narratives the multiple sounds of silence. There was a shifting of their awareness and mine, of the need for silent space, both external and internal. The health professionals were able to tune into or have an awareness of those in their care who needed to enter a quiet space where questions are nurtured and wonder can be revealed, and they move into compassionate action. Knowing when to wait, when to talk, when to listen, allowing the moment to evolve and for it 'just to be'. They created the right relationship to reconnect wholeness for that person, thereby enabling them to heal. Healing the dying may sound oxymoronic but healing does not mean 'to cure' in this context but rather to bring various parts of the self into a whole relationship, a sense of an integrated self and life. Dying is then perceived as a part of life, fitting into a broader philosophy that gives both death and life meaning.

In essence, exploring the phenomenon of silence in this research revealed six separate but interrelated insights:
Silent moments
Silence as suffering and compassion
Silence as connection
Intuitive silence and gratitude
Being silent for others
Silent meaning of symbolic language

These insights have living meaning as they revealed themselves at the time of the analysis. At a different time, with a different reader of the narratives or engaged dialogue with colleagues with whom the narratives resonate, additional crafting of ideas may unfold and further deepen understanding. Therefore, my findings in this thesis should be seen in essence as part of a living document, with living meaning, a base to return to as additional understandings reveal themselves (van Manen, 2014).

The essence of silence was revealed across all health profession disciplines, and patients and their families, in this research and in understanding this phenomenon, we contribute to human caring, by presenting a unitary world view. Sitzman and Watson (2014) and Watson (2008) see this as exploring the sacred nature of the inner life world – of subjectivity and humanitarian wholeness. A unitary ontological epistemology is significant as it informs multiple ways of knowing, being and becoming (Watson, 2008; Watson & Smith, 2002). 'Caring science' as mentioned in chapter 3, is centred in connectedness, positioning human caring as central to science, art and humanity. Reed (2017) suggests "unitary ontology in nursing refers to the holistic nature of human beings, described as more than the sum of parts and integral with the environment in a process of ongoing and innovative change" (p. 260). Considering the role of silence in holistic practice adds to our understanding of this being an essential element of caring, leading us as health professionals to create the right environment for healing to occur if it is meant to.

Silence has a multitude of meanings and therefore is a very difficult concept to define. Jaworski (1993) suggests we ought not try to define silence because its essence is too ambiguous and too expansive to ever be pinned down to a strict definition. He is concerned for its function rather than structure, and he is more interested in how silence works than what silence is. I take Jaworski's point, as the participants in this research revealed their lived experience of silence within the palliative care context with six separate but interrelated living meanings. However, if the research was broader, silence would emerge further, building on its meaning, use and experience. Possible examples of this would be the silence of the oppressed, silence as it relates to music and language, meditation, cultural silence and the use of silence in covering up issues or situations. Silence is broader than the absence of sound and it is anything but empty, when I reflect on the narratives offered in the previous chapter. Downie (1994, p. 184) also supports my thinking when commenting that "definitions can be

undesirable if they foreclose speculations". Being open to my participants' lived experience of silence highlights how silence reflects what silence is to them.
In Chapter 2 I delved back into ancient Greek times and the beginning of Western medicine, and the teachings of the great physician Hippocrates and the God of Healing, Asklepios (Kearney, 2000). I return to these ancient times to consider the early concepts of silence and the role of Harpocrates, the God of silence, secrecy and confidentiality. Statues of Harpocrates portray him with one finger over his lips as a gesture of silence, but this stance has also been interpreted as a symbol of his youth, sitting with his finger perhaps in his mouth in a childlike stance (Hall, 1977). He is seen as a symbol of a passive, mysterious, or empty silence because of the mystery surrounding him. In contrast, the Goddess Larunda is symbolic of an expressive silence, attempting to communicate without speech. This is the silence that speaks lounder than words (Schwartz, 1999). Larundic silence sits philosophically with hermeneutic phenomenology because Larundic silence requires interpreting to make communication possible.

Bindeman (2017) offers a phenomenology of silence in his book on the works of Heidegger and Wittgenstein. He describes silence as an empty phenomenon which may be considered as Harpocratic because it is mysterious. Bindeman (2017) suggests in this state, it may be viewed as reflective silence as it invites self-exploration. In chapter 5 Shaun and Carolyn offered consideration of this in their narratives, where they reviewed their lives from a patient's perspective (p. 119-120) while Sharon and Margot (p. 98-100) offered consideration of silence through a health professional lens. Their experiences of silence were not of an empty silence, as it was full of thoughts and ideas as they reflected on life. Therefore, reflective silence is not purely silent but may be mistaken as such, because it offers no outward communication. In the role of researcher I reflect back on my journal entries when I feel invited or compelled to reflect on my interviews and observations, and this process reawakens knowledge I may have had already, but overlooked, or raise further questions to invite new learning and understanding. Harpocratic silence therefore offered an active response to construct meaning for silence in this context, enabling a growth of ideas.

The consumers of palliative care in this research often asked, commented or reflected on the difficult to answer questions at the end-of-life, when all too often there are no answers to the mystery of life. The issues are existential or profound or too big to consider, so as health professionals we need to learn to sit comfortably with the unknown and be open to quiet reflective thinking, as Bindeman (1981) offers “silence sets the thinking in motion” (p. 1). When we are thinking we are searching for possibilities, to make sense of the unknowable, to find order in this silent space. Bindeman (1981) states “we cannot know silence because we cannot know what it is. But we can describe the effects of silence” (p. 54). Harpocratic silence therefore is passive until we examine it, and in this silent empty space we create the meaning we are looking for.

Larundic silence, in contrast, implies a full or active silence. These are expressive silences, as Larunda communicated to Hermes. They have intentional meaning and offer communicative expression but rely on hermeneutic interpretation to make their ideas known. This can be problematic, as when we interpret, we do so with our own pre-understandings, and therefore run the risk of misinterpretation if we are not open to deep listening to fully understand what is going on in the silent moment. This can be seen in Edith’s narrative (p. 93-94) when referring to her son with his multiple health issues and she makes the comment that *“nobody pieced all the pieces together”* until then he was seen by the *“young Asian guy”* [Doctor] who watched and listened and skilfully assessed his needs. I note also, from my reflexive journal:

> John walks into the service, bent over with stomach cramps, pale and sweaty with pain and his face masked by the blue ice cream container, now dubbing as his vomit bowl. Likely bowel obstruction from his cancer requiring pain and nausea relief, as people swing into action to fill a syringe driver with medication, I sit with him, cool face cloth to his sweaty brow and gentle rubbing of his back as his head stays firmly fixed to the depths of the ice cream container, not really a time for talking, we are silent in the acknowledgement of these wretched symptoms, we wait for relief to come. I am unsure why I break the silence to ask – “what is the one thing that I can do right now to best help you?” A rather shocked look on the face of the med student standing awkwardly in the room, as

> if to say ‘isn’t it obvious’. “Find my son” was the reply. Med student and I exchange glances and wait for the clarification to unfold, a gentle – “go on” I encourage. Three years back, they gave their son a kayak for Christmas to enjoy on their summer holiday at the beach. The boy was lost at sea and his body never found, we are silent in the horror of this tragedy. The physical distress he was experiencing was nothing compared with the emotional suffering and his guilt was palpable. Med student and I talk afterwards about the benefit of asking open-ended, seemingly naive questions as I acknowledge his initial dismay at my question, we gain so much in understanding what is important for people if we do not concentrate solely on the physical symptoms.

I am aware John’s story may well have come out during this man’s time in the service as the staff are skilled practitioners. Once his physical distress was better managed, both parties would be in a better space to explore this further.

Larundic silence can be difficult to interpret because we rely on information at hand, and it takes greater effort to find the relevant silent meaning to reveal the things we do not already see. When interpreted well it is enormously helpful but if misinterpreted, it has the possibility of doing harm. Gadamer (1985) suggests that there is meaning constructed in interpretation that is different from meanings offered by individual components, hence it is not possible to claim that the meaning is what one person says it is, no interpretation can be truer than another’s. Therefore the truth of the meaning can vary and change but Gadamer argues that there is a ‘thing-in-itself’ which remains constant, despite change. There are overlaps because each interpretation must have input from the continuous thing-in-itself. Encountering the expression ‘the nature of things’ the point is clearly that what is available for our use and given for our disposal has in reality a being of its own, which allows it to resist our efforts to use it in unsuitable ways. Or to put it positively: it prescribes a specific comportment that is appropriate to it (Gadamer, 2004, p. 70). Gadamer is clear that we accumulate our experiences combined with general history. Hence we all have an individual unique perspective of the world and we use that to interpret the past, understand the present and take that to the future. Health professionals working in the field of palliative care are required to be open to each unique person in their care, no two end-of-life experiences are the same, the philosophy of care is individual and person-centred. Each encounter brings a new set of experiences, beliefs, expectations and understandings to engage with and build onto our body of knowledge to take us forward. We are encouraged to build onto our knowledge of Larundic silence in the context of this research as we learn to interpret the meaning of, or need for silence in the palliative care context. Silence is a difficult concept to grasp and we do not always interpret it correctly, but this too is a learning moment. We do not always have evidence, and are not afforded the luxury of time to go on, we often meet people in the immediacy of their dying time so must tread cautiously to reduce the risk of misinterpretation. A beginning practitioner in the field does not have the experience of history or previous knowledge of the interpretive process to build on, so there is a role to play for experienced practitioners, with education, and mentorship for those travelling beside us in this field.

The hermeneutic circle is helpful for exploring the meaning of silence as I go to and from the transcripts as a whole, to extracts from them to examine in depth and return them to the whole. Remaining open to what is offered, reflect on interpretive meaning and any preunderstandings. Hermeneutics encourages us to question:
". . . constant self-reflections and attempts at self-awareness. Thus only through hermeneutical reflection am I no longer unfree over against myself but rather can deem freely what in my preunderstanding may be justified and what unjustifiable." Gadamer (1976, p. 38).

Larundic silence may be more eloquent than words for emotions and affections. Sandy (p. 106) experienced this when she entered the room as the observer of silence, where the family were quietly present, there was still something actively and meaningfully taking place. Sandy may have tried to figure out what the meaning was, exploring it with questions, but intuitively she recognised the need to maintain the silence, it was a communication tool in itself. It can communicate to the listener a thought that does not need to be expressed aloud. Sandy felt the unspoken bond of a family and experienced this through silence. Larundic silence also played a significant role in the exemplar from my journal of the interconnection of nurse, nurse manager, mother and son (p. 108-109).

The participants in this research reawakened my consciousness of the roles of silence. When our caring practices enable a person and their family to get to a point where nothing more needs to be said, when issues have been resolved, affairs and relationships put in order, there is a freedom of just letting things be. Larundic silence is enough to let those around know that everything is all right. Not everyone has this level of peace but when it is witnessed in practice, one is encouraged to assist in recreating the right environment for it to occur, if it is possible, for the next person in our care. In doing so, death can be seen as a normal, natural and peaceful end to a life well lived, a release from any suffering. The narratives offered in this research show how silence is enough, when there is no more to be said and show how silence can be comforting if those around are able to let silence be. Quiet company can be comforting, offering warmth and caring spiritual peace. It can be seen as an act of respectful generosity to perceive the need for silence and not fill it in due to one's own discomfort.

Moustakas (1990) suggests that to understand a phenomenon one has to fully immerse themselves in the phenomenon. This was a continual challenge in this research. I didn't initially intend to explore the phenomenon of silence. If that had been the research focus I would have prepared and reflected on the essence of this work, establishing my focus and preunderstanding before going out into the field. However, it was my participants who took me on this journey of discovery as this was what was important to them in end-of-life care. I had to be open to whatever unfolded so – revealing the phenomenon of silence was an exciting revelation, reawakening my consciousness to the possibilities for care. The multiple roles of silence resonated with my experience as a palliative care nurse and in the depth of exploration, the sounds in silence became louder. I required a depth of personal silence and stillness to manage the bombardment of possibilities within each narrative, within each connection and within the exploration taking place in my reflexive journals. I discovered silence demands full attention, it certainly does when connecting with another, but full attention is also required to silence my own thoughts and feelings. To be usefully silent with another I need to be silenced within. My silence is then open and free to be with another, it offers companionable presence and allows the person I am with, time to process what they wish to say or to feel comfortable in the silent space provided. I am in the role of holding them in a safe space to allow what needs to happen, happen.

When words are neither possible nor necessary, silence becomes a form of communication, like gentle touch or eye contact that leads you into the depth of their soul. Sabbadini (2004) uses the metaphor of silence as “a container of words” (p. 229). I observed this, as the health professionals in this research held those in their silent moments of caring and it resonated with me as the researcher as I held my participants with respectful rapport, having developed a trusting relationship for their stories to unfold.

Silence as the ‘container of words’ (Sabbadini, 2004) I see symbolised as a goblet or chalice in palliative care. A solid broad base representing strong professional footage, grounded in the art and science of our respective disciplines. The thin stem representing our willingness to narrow the focus of care to what is of importance to each individual, acknowledging the essence of person-centred care. The cup, providing the safely net of support as the turbulent waters of the final acts of living can be held safely and learn to settle. There is no lid, symbolising openness and space for resolution, exploration and spiritual contentment.

This symbolism holds the sacredness of the silent moment. It was evident in the story telling for this research from both carers and receivers of palliative care and was common across all disciplines irrespective of whether they identified as specialist or generalist practitioners, the holding was a human-to-human connection. It can also be found in the community stories, the holding of ritual and routine to palliate, to cloak/wrap the person with compassionate caring. The person becomes cloaked rather than the illness.

The findings in this research invite consideration of silence as a component of caring science and the caritas processes referred to on page 62. These processes are not complete without considering silence in transpersonal caring, which transcends the ego and allows for the spiritual connection within the caring moment (Watson, 2005, 2012). Transpersonal caring incorporates consciousness, intentionality, spirit and energy, and therefore requires self-knowing, opening opportunity for higher caring consciousness and intentionality (Watson, 2005). It asks us to consider thoughts and actions of the self when incorporating transpersonal caring into practice. As Watson (2005) suggests, “translating the transpersonal theory into authentic practice, the mind-set becomes one of creating spirit-filled sacredness and reverence around our work" (p.195). Considering the essence of silence in the context of this research, there is a spiritual underpinning to these moments. Spiritual care conversations in daily life include verbal and non-verbal communication but towards the end of life silence is more dominant. To be comfortable in shared silence of spiritual care, requires a trusting, respectful relationship, and trust enables silence to be therapeutically effective. Holding the trust moment and being comfortable with silence where there is no answer, as expressed in some of the narratives, fits with Teahan's (1980) review of Dauenhauer's religious description of spiritual caregiving silence as a silence beyond all saying.

Spirituality, like silence is a difficult concept to define and there is no agreed definition (Nolan & Holloway 2014), although in healthcare it is considered a dimension of life that seeks meaning, purpose and transcendence (Puchalski & Romer, 2005; Nolan 2012). Spiritual care and palliative care are called to recognise and respond to the needs of the human spirit when faced with loss, despair and suffering, as it is stated in the philosophy of palliative care (WHO, 2016). It is individualised, person-centred and asks us to "be with" another on a human-to-human level rather than the task-oriented "doing for" another. Whilst a remit for all health professionals in palliative care, our Chaplin colleagues have historically had the dominant skill set in this domain, whether from a theological, humanist or non-faith based tradition. This has been so, since the early beginnings noted in Chapter 2. Glenda's narrative (p. 116) shows the disconnect that can happen when we verbalise working as an interprofessional team but the lived reality is of a dominant medical discourse where spirituality can be overlooked. Her wisdom and skill set is equally as important in end-of–life care, especially around the importance of silence where it is sought and respected in many faith and spiritual traditions. Such reflective disciplines, chaplaincy and nursing for example, are more acquainted with silence. The quality of care and support that can be provided by this professional stance, reveals the sometimes neglected interplay between disciplines.

Clayton (2013) on writing of his experiences as a Chaplin in a children's hospice, acknowledges the importance of a quiet, contemplative, reflective, internal space as a prerequisite of care. This silent space offers opportunity to focus on the notion of presence, and paying attention to what is happening. He notes this attentiveness can draw one into the child’s world, enabling one to engage with him or her in the moment, and it communicates in unspoken ways that we value others (p. 39). The distinctive and creative value of this approach is described by Henri Nouwen, who speaks of the friend who cares as one who can “stay with us in an hour of grief or bereavement, who can tolerate not-knowing, not-curing, not-healing, and face with us the reality of our powerlessness” (Nouwen, 2004, p. 38). This is the place palliative care health professionals and families operate from on a day to day basis. Clayton (2013) also offers from his experience that:

> The simplicity of a contemplative stance is what enables it to cut through the obstacles and boundaries to be found in more conceptual approaches and may account for the connections established between contemplatives of different faith traditions such as the Christian, Thomas Merton, and the Buddhist, Thich Nath Hanh. In a hospice setting it is vital to travel with integrity beyond the boundaries of particular faith communities as well, for this is where a majority of the families dwell. Unlike more didactic approaches to faith, the self-denying attention to stillness and the present moment is precisely what generates a depth of professional practice. (p. 46)

I was encouraged by the research undertaken by Bassett, Bingley, and Brearley, (2018b) who investigated the nature, meaning and value of silence in spiritual care-giving at the end of life, from the perspective of palliative care chaplains. It did not include other members of the health care team but examples of silence in care-giving offering comfort, a deep sense of intimacy and connection, its use as a form of communication and healing resonated with me personally and the findings from my research. They discovered there had been no research into silence in spiritual care at the end of life before undertaking their study and I believe their findings are helpful across the palliative care team for consideration. ‘Being’, ‘being in’ and ‘being with’ silence and observing the outcomes of acceptance, restoration and peace support us in palliative care practice. Emphasising the role of silence in the holistic nature of care, foundational to palliative care practice and philosophy, a way of being with another.

Reconnecting the living meanings of Silent moments, Silence as suffering and compassion, Silence as connection, Intuitive silence and gratitude, Being silent for others, Silent meaning of symbolic language, I return to the early pioneers of palliative care where Dame Cecily Saunders attributes her idea of 'total pain' to her quiet listening to those in her care:

> Well I knew from what patients were saying that this wasn't just a physical problem and I knew from my previous nursing and social work that anxiety and depression were major components. I was certainly alert to the fact that family problems were difficult, very often adding to distress and I also felt that a search for feeling that they were wanted and still important people was a spiritual pain and so, out of what one patient said, very neatly describing her pain to me, developed the idea of 'total pain' with those four components. And that seemed to me to be a structure that, although it was a whole package as far as the patient is concerned, it was almost an internal checklist for you when you are listening to them to spot the main problems of their suffering. (Clark, 2018 p. 79)

The idea of 'total pain' having an holistic lens and incorporating spiritual dimensions of personhood was carried forward by Balfour Mount in Canada who had also been influenced by the work of Eric Cassell. Mount (Kearney & Mount 2000) argues that the relief of spiritual pain requires awareness of four dimensions of care. A relational dimension (referring to the therapeutic relationship and the respect for the patient's otherness); a physical dimension (effective symptom management); a psychological dimension (taking a biography and identifying sources of meaning, examining fears and anxieties of the unknown) and a spiritual dimension (transcendence). For Mount, 'celebration of the transcendence' is a 'healing connection', an experience of integrity and wholeness that comes from a connection with anything larger or more enduring than the person (Mount, Boston & Cohen, 2007, p. 386). The earlier work on transcendence by Cassell (1982) offers:

> Transcendence is probably the most powerful way in which one is restored to wholeness after injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is bought closer to a transpersonal source of meaning and to the human community that shares that meaning. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension it is deeply spiritual. (Cassell, 1982 p. 644)

Shelia Cassidy (1988) considers spirituality of caring from the carer lens, helpful for health professionals and family caregivers, in her book *Sharing the Darkness.* Her tussle with spirituality is from a personal perspective from being prisoner in a concentration camp in Chile during the Pinochet regime in 1975 and hospice medical director in Plymouth. She considers:

> The spirituality of the companion, of a friend who walks alongside, helping, sharing and sometimes just sitting empty handed, when he would rather walk away. It is the spirituality of presence, of being alongside, watchful, available, of being there.'… (and a companion) must enter into their darkness, go with them at least part way along their lonely and frightening road. This is the meaning of compassion (Cassidy, 1988 p. 4-5).

Cassidy's spiritual care is presence, at times silent as she cares for those who suffer:

> Right at the heart of suffering is the grace that sustains us all, carer and cared for alike. It comes as freely and as surely as the sunrise piercing the blackness of grief and despair restoring once again the hope of things unseen. (Cassidy, 1988 p. 164)

Michael Kearney shares stories of pain, death and healing in his book *Mortally Wounded* (1996). He also spent time with Dame Cecily Saunders and discusses soul pain occurring when a person is cut off from the healing power of their own inner depths. He sees the soul as the living connection between the surface and the unfathomable and meaning-rich depths of who we are (Kearney, 1996, p. 59). Both Saunders and Kearney connect soul, silences and intimacy. And Doyle (1979, p. 58) writes:

> Ministering to the dying is in essence sensitivity to what each individual is going through in this particular crisis. There are no special techniques to be learned, no routine questions to cover one's own anxiety, no one attitude that will fit every situation. This service may consist of sacramental acts, private conversions, or simply being present to the other in shared silence.

From the ancient wisdoms and early pioneers of palliative care to the voices of the participants in this research, I was invited to consider the importance silence has as a significant role in supporting deep and meaning filled communication, understanding and compassion at the end of life. However, in the business of everyday practice, paying attention to, or acknowledging or developing this gift of awareness is challenged. Health professional participants felt that palliative care is losing its way, possibly a result of the pressure to meet the demands on the service with time pressures dealing to the tasks at hand taking over the connected silent moments of 'being with', returning to the' doing for'. Randall and Downie (2006) certainly argue that the common rhetoric of palliative care does not match the reality of practice. They refer back to palliative care having patient-centred values and ideas, with Dame Cicely's vision demonstrating Asklepian principles but suggesting, like the health professional participants in this study, the specialty of palliative care has become increasingly Hippocratic. While there is an emphasis on listening and communication skills, on concentrating attention on the individual person, in practice, structured interviews, assessment tools and questionnaires are encouraged. Referring to assessment tools they offer:

> The term expresses the sad delusion that, like the surgeon's scalpel, the assessment tool is in itself an effective intervention. In other words, palliative care professionals, instead of listening to the sick patient's needs, fears, and wishes, and accepting these at face value, are encouraged or exhorted to impose professional templates. (Randall & Downie 2006, p. 20)

When considering spiritual care, they challenge whether this can be done with assessment tools. Instead they argue for a relational approach, which I fully support, where just for a time, life, is not about dying but where space and silence contain unconditional grace, respect and presence. Where we turn to the human-to-human connection, attention, listening and creating a safe space to hold the dying.

This human-to-human connection focuses on person-centred care as it acknowledges the value of the human relationship as healing (Sulmasy, 2002). The importance of listening to the person and their story. Silence becomes the prerequisite for listening (Savett, 2011) and silence is identified as a component of compassionate nursing

(Buchanan-Barker & Barker, 2004). Palliative care is holistic care and is grounded in an inter-disciplinary and biopsychosocial-spiritual model of care (Sulmasy, 2002) not only for the person/patient but including the whole family unit. Hence, this research engaged with a range of participants, people and their families receiving care and a range of health care professionals in the inter-professional teams working in a range of areas; hospice, hospital, aged residential care, community and day care settings. The lived experience of the importance of silence transcended across all people in all settings, illuminating the need to reengage with this meaning making, human-to-human healing connection.

When considering the living meanings of silent moments, silence as suffering and compassion, silence as connection, intuitive silence and gratitude, being silent for others, silent meaning of symbolic language and, extracting myself from the depth of meaning to a wider world view and reconnecting with the stories as a whole, I re-emerge with the notion that compassionate caring is at the heart of enabling deep listening to occur, and the sustainability of compassionate caring is the question to raise when the pressure of service delivery threatens this essential essence of care. We inadvertently revert back to a task-orientated approach rather than person-centred, for survival in busy times. The emphasis is on targets and systems rather than people. If health professionals feel undervalued by the system then it is difficult to keep compassion to the fore. We cannot be compassionate to others unless we are compassionate to ourselves first – the cycle of challenge is exhausting. Staffing shortages do not help in bringing greater humanity into the systems. Health care services or management thereof are not a subset of the service, from a holistic sense the system in which we work is of equal importance to those giving and receiving care. It is outside the scope of this research to investigate the system as such, but I support Habermas' (1984, 1987) system theory, where he describes the system being as important as the people in it. He believes in the importance of critical self-reflection and acting on that reflection for the greater good of others. The use of self-reflection to consider what is happening around us overcomes self-centeredness and leads to a change in society, believing in the importance of dialogue and reflective action to overcome such challenges. Dame Cecily Saunders' vision for her pioneering work for palliative care, took place at a time of enormous change in British society and the advent of the National Health Service, and was appealing during the time of organisational turmoil where hospice offered a structure where people coming to terms 'through acceptance of the life one has lived comes an acceptance of death' (Breitbart 2008, p. 212). However, providing compassionate palliative care in health systems that are fiscally driven is challenging. Britain has lived through these challenges in 2013 with the Francis report on Mid-Staffordshire NHS Foundation Public Trust Inquiry https://www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry and the Liverpool Care Pathway for Dying Patients https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients where poor standards of practice were directly relevant to the place of compassion in palliative care. Media reports and health care literature all use lack of compassion as an indicator by which inadequate standards, lack of care and neglect have been judged (Newdick & Danbury 2015, Gallagher, 2013). Therefore compassion is an essential quality and competency that people seek for the vulnerable and those facing the end of their lives.

Silence has a different meaning in this situation, but in our silent and critically reflective moments, we are compelled to act to ensure these stories are not repeated and we invite humanity back into our health care practice, reigniting the metaphorical lamp of compassion in our institutional darkness. The work of Robin Youngson (Co-founder of Hearts in Health Care https://charterforcompassion.org/robin-youngson) in New Zealand supports this approach, suggesting it saves time and money and enables health professionals to recapture their professional pride in their work (Manchester, 2012). It was evident in this research that the health professionals were feeling challenged and unsupported by the system. Feeling demoralised by what they identified as important for good practice but also feeling disempowered to fully commit to holistic care, they concentrated on physical symptom management due to time pressures. A sense of weariness and compassion fatigue begins to creep in to the reality of practice. I mentioned on page 137 an example of where expressing the honesty/reality of practice, was a story told off tape which I could not ethically explore further, leading to what lies in the shadow of silence? If we do not uncover the troubled sounds of silence in the systems we work in, compassion fatigue deepens and we risk a repeat of the troubled examples that unfolded in Britain as cited above.

I return to the New Zealand context of palliative care vision, with the national strategy published by the MOH (2001) and subsequent documents referred to in Chapter 2. The guiding frameworks, policies and projections of future needs, the development of Te Ara Whakapiri and Advanced Care planning, the continued support from Hospice New Zealand and funding support from District Health Boards and charitable community donations, all guide service provision. Despite the vision outlined in these documents, the tide of discontent and tiredness is palpable and compassion fatigue evident in the silent moments of deep reflection from the health professionals in this research. The brave positive exterior belies a different story within. However, the consumers of the palliative care services did not identify an issue. They were grateful for the care and attention they received, their needs were largely met, and they shared silent moments with their health care providers which were supportive, therapeutic, connected and compassionate. It was the health professionals who indicated more could be done, and that the consumers of the service where not always aware of what could be offered. None of the consumer participants' in this research knew of the philosophy of palliative care until they read it as part of the research information package (see appendices). Had they done so, and become aware of the holistic nature of care and the interprofessional teams available to them, they may have offered further critique of service provision.

The community as a whole, is also an important player in end of life care that has become marginalised. What if we could use the community more, by returning the final acts of living to the community we live within, could this community of care be the bridging saviour, to relieve the pressures on the health professional community? Placing the care of the dying back in the community and highlighting community engagement may be a helpful pathway in the future to manage care and support and understanding of what is important at the end-of-life. It might also invite respect for the role of community and respect for each other as health professionals, as we watch and learn on both sides of the experience. It may also break the uncomfortable silence surrounding discussing death and dying, as the community reengages naturally with its understanding of the life cycle as it did in earlier times, referred to in Chapter 2 where community care predates professional care of the dying.

Communities hold valuable resources and abilities and provide the social relationships so important to personal lives, yet the dominance of health care professionals caring for the dying means, we have inadvertently pushed the community into a narrow support role evidenced by service clubs, volunteers and support groups that so willingly contribute to fundraising and other needs of hospice services. Insights were offered into the role of community beginning with Patricia's story (p. 6) where the restaurant was supportive in maintaining care, routine and ritual at the end-of-life, the death café (p. 139) and bakery story (p. 141) all contributing willingly to supporting a community of care.

Allan Kellehear (2005) notes that care of the dying in the past has been a normal and routine matter for families and communities and that there is a need for public education for normalisation and routinisation of dying in the modern experience of health care and death (p. 14). He offers seven themes of normalisation, including community relationships, whole person care, the person as social unit, safe involvement, prevention and the need to go beyond health service ideas, as building blocks of a public health approach to end-of-life care, believing public health cannot ignore death, dying and grief. These themes offer the positive aspects of caring for the dying, brought down from Western history with its sources in community and the healing professionals in churches or science (p. 15). A public health approach to end-of-life care is guided by the WHO idea of the Healthy City (2015). Kellehear (2005) refers to the Healthy City that cares for each other at the end-of-life as the Compassionate City. The guiding documents for palliative care in New Zealand referred to in Chapter 2 are missing this compassionate ethos. I raise the notion here for consideration for future planning to support a human-centred approach to our community of care.

WHO uses the Healthy Cities definition of Hancock and Duhl (1988) that focuses on the "process that creates the possibility of health in people" instead of an end state. They felt that a Healthy City could not be described by tables of data but had to be experienced (p. 3), resulting in 11 characteristics of a Healthy City: A clean, safe physical environment; a stable and sustainable ecosystem; a strong, supportive and non-exploitative community; high degree of public participation in and control by the public over the decisions affecting their lives, health, and well-being. All people will have their basic needs met; have access to a wide variety of experiences and resources, with the possibility of multiple contacts, interactions, and communication; a diverse, vital and innovative city economy. There is encouragement of connectedness with the past, with the cultural and biological heritage, and with other groups and individuals; a city form that is compatible with and enhances the above parameters and behaviours; optimum level of appropriate public health and sick-care services accessible to all; and have high health status (both high positive health status and low disease status).

Building onto the Healthy City concept, Kelleher (2005, p. 46) characterises a Compassionate City as having local health policies that recognise compassion as an ethical imperative to health. It does this by meeting the special needs of the aged, those living with life-threatening illnesses and those living with loss. It has a strong commitment to social and cultural differences by involving the grief and palliative care services in local government policy and planning. It offers its inhabitants access to a wide variety of supportive experiences, interactions and communication, promotes and celebrates reconciliation with indigenous peoples and the memory of other important community losses, provides easy access to grief and palliative care services, has a recognition of and plans to accommodate those disadvantaged by the economy, including rural and remote populations, indigenous people and the homeless, and preserves and promotes a community's spiritual traditions and storytellers.

There is a fine line between visionary ideas however, and practical policy and application, but contemporary palliative care could be encouraged to consider this further, moving away from the focus on clinical physical care, to leading a compassionate public health approach to rebalance the Asklepain, Hippocratic, Harpocratic and Larundic traditions.

Compassionate caring silence was identified as one of the insights in this research. There is a distinct human need for compassion in human suffering. Compassionate Cities is not literally about cities but a community of care. There are challenges to this idea but challenges should not default to not trying! One such challenge would be in attempting to introduce the compassionate city concept on a large scale. Beginning with small localised services for change, building on social capital, relationships, trust and cohesion in a community is the basis for learning how to transform larger systems. As Robert Theobold (1997) reminds us, there is evidence that the connections between small-scale shifts in thinking and action are the building blocks for more fundamental change we need.

Public health initiatives are implemented by health professionals because they have the knowledge and expertise around the benefits and risks to society. Professionalism in care of the dying has led to a view of death as a series of problems from illness or disease that could or should be dealt to by professionals, leading to increased institutional care. The palliative care philosophy has tried to rebalance this notion, seeing dying as a natural process and experience that could or should occur in an environment of the person/family's choice. But the reality of the person's choice being feasible is so often challenged for a variety of medical, social and emotional reasons and there is no right way. But there does need to be a respectful rebalancing of professional and community relationships to enhance care and understanding at the end of life. Kellehear (1998) refers to the apathy of public health to address death and dying, believing it is someone else's problem, a death-avoidance style of thinking. While public health maintains this stance and palliative care focuses on the clinical management of people's lives, engaging the community in end-of-life care will remain a challenge. Kellehear (2005) offers consideration of this challenge by saying "end-of-life care will become one of the single greatest challenges of an aging, mobile, multiculturalist society in the twenty first century . . . that approach and that challenge, is the promise of compassionate public health" (p. 115). Death and loss are part of our lives, reminding us of our cultural, spiritual and political responsibility to each other. Inviting compassion into our economy, society, health, law and moral conduct benefits our shared experience of the fragility of life.

I return once again from the broader consideration of future directions of end-of-life care to the intimate nature of silence, a gift offered to me from the participants in this study. This is highlighted in a Talmudic phrase 'the voice of fragile silence' and the Christian term 'the still small voice' (Heschel, 1955). Through listening to this voice, we become attuned to our personal motivations, reactions, and reflective learnings with wisdom for the appropriate way forward in a given context. The pathway for me to arrive at this point was guided by engagement with phenomenology as my research methodology where van Manen (1990) offers, “hermeneutic phenomenological reflection deepens thought and therefore radicalises thinking and the acting that flows from it” (p. 154) and refers to hermeneutic phenomenology as a “critical philosophy for action” (p. 154).

The Phenomenological Pathway

I wished to explore phenomenology as a research methodology and build on my developing knowledge of it. Its philosophical approach concerned with the meaning of human experiences was congruent with my nursing philosophy in palliative care and the philosophy of palliative care itself. This interconnected synergistic relationship allowed me to stand authentically in the research space, a value I hold dear. The early philosophers described phenomenology as a way of thinking and as new ideas and developments built on to the early beginnings, its primary concern was for the nature and meaning of human experience. As I set out to explore the lived experience of people giving and receiving palliative care so that knowledge gained could be used to navigate a path to our future, I acknowledge it was a broad topic from which the participants took me on a journey, bringing to the forefront of awareness, the importance of silence. Silence made its presence felt. On the surface, it may appear simple but it is profoundly important, with complexity of meaning and need from both givers and receivers of palliative care. Silence unfolded due to phenomenological exploration, allowing me to gain insights into the meaningfulness of this human experience. Burch (1989) implies that one of the benefits of phenomenology is found in what the method ‘does to us’, it seeks a “transcending theoretical understanding that goes beyond the lived experience to situate it, to judge it, endowing lived experience with new meaning” (p. 192). Understanding the importance of silence, I regained knowledge from what I now understand was on a superficial level. I respectfully acknowledge my need to appreciate, learn from and pass on with new meaning in my teaching role, in order to improve end-of-life care. Phenomenology offers the opportunity to study the human experience from the context of the lifeworld, the stories offered by participants were rich and meaningful and through reflexive engagement I was able to weave in and out of the hermeneutic circle of care for each narrative to connect the pieces with the whole of their meaning. The methodology allowed me to connect, listen, observe, reflect and unfold new insights and possibilities. It created a sense of wonder which was also perplexing, why had I not considered the depths of silence before now? “Silence was staring back at me”. Van Manen (2014) offers: for phenomenological text to “lead” the way to human understanding, it must lead the reader to wonder. It was writing that offered the space to explore the perplexing wonder, not to understand it but to experience it as the essence of silence touched me, inviting me to see, with a desire to share the importance of this concept in practice. The participants shared life while reflecting on it, a sacred gift.

The utilisation of my reflexive journals (eight in total, encouraged in phenomenology) has offered another level of thinking and engagement with text. They enabled me to explore my writing and thinking and relevance for practice. My journals have become precious companions on this journey of personal and professional growth, as noted in one of the entries:

> I wrap myself in silence on this moon filled, starry night. Sleep leaving me for now as I surrender to chaos in my mind, why have I not considered the depths of silence until now? A stirring within, as I’m drawn into the depths of its meanings. Perhaps in the silence of the night I am being asked to live through the idea that silence and darkness does not bring about sleep, a common bedside scene for families watching and waiting, my mind is not silent from the possibilities, it is accompanied by the hum of the fridge, the ticking clock, the erratic sounds of irregular breathing from the dream time of my man that was invading my thinking space. I get up with you as my companion as we moon bathe together . . . outwardly I am exhausted . . . inwardly I am inspired . . .help me now, to find the stillness to ‘just be’ with silence so that I can learn to trust it, to skilfully use it as a therapeutic modality of my caring until the heartbeat is silent in the final act of living.

Buytendijk once referred to phenomenology as the “science of examples” (van Manen, 2014, p. 257). The narratives and reflexive journal extracts used as examples in this work may be used as rhetorical and aesthetic presentations for evoking phenomenological insights into silence, that is a concept that can be difficult to articulate with clarity, doesn’t always have a voice, where it can be difficult to grasp the unique person-centred meaning, and which cannot be explicated in a straight forward manner. The examples in this methodological text focus on the phenomenon itself.

Examples often take shape as a story, this methodology allowed me to keep whole ‘chunks’ of the narrative together, some longer than others, which fitted my need to be respectful of these gifts offered. The examples also held deeper evidential significance as each narrative was an example of something experientially knowable or understandable even if not directly expressible when given room to stand in its own space. The living meanings of Silent moments, Silence as suffering and compassion, Silence as connection, Intuitive silence and gratitude, Being silent for others, Silent meaning of symbolic language, unfolded as the lived experience from my analysis. However, I invite the reader of this work to consider these examples, and use them as a catalyst for their own reflection and learning, and perhaps also delve into a hermeneutic journey as the concept of silence is revealed to them, continuing to build on to the living meaning of silence, and use it to improve care. Participants in this research highlighted for me that in silence we hear our own internal voice, we dialogue with life and hear the beneficial sounds, nurture our curiosity, bringing heart, light and soul back into the busy institutional darkness. In silence, the eye of the heart sees the quality of being fully present in the needs of another and demonstrates “I am here for you”. Phenomenology is about explicating meanings as they are lived in our everyday world, it provided for me a more rigorous account of how silence is experienced, interpreted and understood in the lives of people giving and receiving palliative care. It offers unique outcomes that are personal and professional. I have enjoyed this exploration, valued the learning, and will continue to build on my understanding of it to highlight the lived reality of those in my care.

The intention of this chapter was to weave through the wisdoms offered from the participants in the research, consider the reflections in my reflexive journal, and return to the literature to explore and support, or challenge these learnings, and offer opportunities to reflect on the implications for people giving and receiving palliative care and the role the community may have in the final acts of living. The concluding chapter that follows will offer some reflections on the research journey and recap the significance of the findings that emerged from the participant’s stories.

Chapter 8 Conclusion

Leadership is practiced not so much in words as in attitude and in actions. -Harold Geneen, Managing.

In this concluding chapter, I reiterate the key insights that emerged from the participants' stories and offer reflection on the research journey I have undertaken, along with the implications for practice and further research, noting strengths and limitations of this study. By writing the conclusion I bring the study to a close but it does not complete the learning that I will take forward in practice and in teaching. The circularity of phenomenology, where the interpretive experience of understanding the text as a whole in order to understand its parts and then to understand the parts, to understand the whole, will continue to invite reflection and learning to lead an improved way forward. Rather than building on my knowledge from a naive understanding to a fully developed understanding, building upwards, hermeneutic phenomenology deepens my understanding in circular ways, incorporating reflection. I emerge richer for the experience. It is a never-ending discovery of possibilities and new insights that energise thought and possibilities.

Returning to the beginning

I began with the intention of exploring as a researcher, the palliative care community of care. To gain insights from the lived experiences of my colleagues, health professionals involved in palliative care delivery, and the lived experiences of the person and/or family who were receiving palliative care services, to uncover the meaning that people give to these experiences. The insights gained may identify unmet needs or opportunities for the provision of palliative care, and better support people living with dying into the future. I was interested in working with a phenomenological lens to develop a deeper understanding of this methodology as it appeared to fit with my philosophical framework as a palliative care nurse and education facilitator. I had a desire to further develop my understanding of this methodology and its applicability for palliative care research. I also returned to the early beginnings of the history of end-of-life care, to the paths well-trodden to gain insights as to the path for our future.

The lived experiences I was offered in undertaking this research were humbling. I was taken on a journey of deeper discovery about what was important to the participants on this journey. I listened to accounts of the caring that each person received, the compassion and respect offered to those receiving palliative care, that forms the core values of the palliative care community, and the partnerships that are formed between the individual people, family and healthcare professionals. The essence of silence, compassion, connection and right relationships, as powerful forms of communication and care, revealed their connectivity to all groups which stimulated my own reflection on the value of these essential qualities of care in the final acts of living.

Reflections on the journey

Phenomenology calls for one to be open to changing directions and exploring the data that is not always obvious at the onset of the research (van Manen, 1997). When I gave full attention to being open to the process and trusting in the direction the participants were taking me, a constructed journey began and the importance of silence revealed itself. The profoundness of this seemingly simple concept has, I suggest, been hidden in the fast pace of life in our palliative care community. Pressures to meet demands, targets, follow protocols, be budget minded and work with limited time and resources encourages a fast pace of care and connection. Without intentionally neglecting the need for quiet reflection, ‘being with’ moments of right relationships with people living their final days/weeks, the art and grace of our practice gives way to addressing the technical competencies of caring. Necessary? Yes, but this does not address the holistic care the philosophy of palliative care practice espouses to, nor addresses the total needs of those we care for. In Cecily Saunders’ (2005) book, *Watch with me*, she describes the caring role:

> Our most important foundation of St Christopher’s is the hope that in watching we should learn not only to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen, and how to just be there (Saunders, 2005, p. 28).

I was humbled by the willingness of participants to engage in this research. However, I was concerned by the ‘gatekeeping’ experienced in some hospice services as noted in chapter 4. Gatekeeping is mentioned in the literature and I felt concerned when I lived this reality in this research. People are keen to have their voices heard and are capable of making their own decisions if fully informed. This is a respectful stance that as health professionals we must remind ourselves of from time to time in our busy working lives, as our professional certainty can get in the way of creating the shared story in working towards a common goal. In a shared vision we demonstrate commitment and connection and consciously understand the person's journey and the professional meaning within the ever changing context of living and dying. I acknowledge that bringing the stories of the recipients of our care to the fore, threatens certainty and control on the part of the health professional. Yet in palliative care the only certainty is that the person will die, but each of the person's experience is unpredictable and uncontrollable along the way. Uncertainty is a given and control an illusion.

There is a heavy emphasis in today's health system on precision, routines, protocols and pathways to maintain control and quality. This system tries to make routine the intensely personal, unknowable and unpredictable experiences. We become limited by biophysical values. This in essence was raised by the health care professionals entering in to this study and as I listened to the challenges faced, I reflected on the need to embrace uncertainty and respectfully acknowledge our inability to control the outcome. In doing so we become more creative and mindfully share the goals of those we care for.

Research design

Participants were interviewed only once and transcripts read and reread, and tapes listened to, unfolding the meanings of the text as a whole, delving deeper into the parts and reconnecting with the whole. Keeping a reflexive journal was key to exploring my understandings. Reflexive journaling also added depth and rigour to the methodology for this research. It was in the journals that I became conscious of an additional level of privilege I held as researcher with my colleagues that I hadn't been clearly conscious of during the process. Being a researcher is always a privileged position as people so willingly engage with us to explore ideas and build a new or better way forward. As a palliative care nurse researcher, I was granted another level of privilege. By this I mean, when entering into a service where people had put aside time to speak with me, 'life' got in the way on a few occasions where good intentions gave way to the needs of people in their care needing to come first. This meant I was able to 'roll up my sleeves' to assist in ways to support the key practitioners to attend to care so that we could reconnect with the research interview when the immediacy of the issue was resolved. This is where I observed practice and was able to offer support. The example of the mother and child story (p. 106) being there to observe practice and suggest a letter was written to the son for his future reference illustrates this. When I supported the gentleman vomiting and in pain, but was able to role model to the house surgeon the importance of an holistic approach to care, inviting discussion afterwards (p. 145) provides another example. As I made cups of tea, checked medications, engaged informally with the teams, assisted in a bed wash to meet comfort and hygiene needs for a fragile person in their own home, and support family afterwards over the tea cups at the dining table, I entered another level of engagement. At all times aware I was a guest, acting ethically and with respect for those I was journeying with. There was a shared understanding that my knowledge and experience in the field of palliative care meant I could be useful and supportive to practice when it was helpful to do so. I valued the trust the practitioners had in me to bounce between the role of researcher and supportive colleague on the few occasion's this was helpful.

I am mindful of being wiser after the journey and appreciate that for a phenomenological study, only a few participants are required to receive rich descriptive meaningful data. Because I did not reveal this research was intended for consideration of a PhD, as mentioned on page 67, and I was largely known to my health professional colleagues, I made myself available to anyone and everyone who wanted to contribute their experiences. This was not helpful as the volume of data became overwhelming and created a challenge for how to honour the contributions so willingly given. I have utilised the transcripts that gave clarity of voice in this thesis, but the essence of what they were saying was also reflected in the stories that did not make it into this thesis. The process of reviewing and checking the data many times was long but robust, confirming and validating the voices chosen.

When day care services were running in some services, one or two patient participants consented to being interviewed, but word quickly got around that others wanted to offer thoughts too. An informal group engagement took place that was outside the scope originally intended but I appreciated they needed to be heard. I utilised my reflexive journals to reflect on the insights gained from these gatherings.

Being a guest in a family home for interviews was humbling and more in line with the intimacy of phenomenology. In future phenomenological research I will ensure a refined limit on numbers of participants. I also felt supported by the phenomenological process, in that it enabled flexibility to refine the research, given I met a bend in the road where the participants wished to journey in a different direction from the road I had anticipated travelling on.

Writing as method

The writing up of the process was a challenge. From a phenomenological point of view it had to do with the constant cycle of thinking and rethinking, writing and rewriting and the relationship of the parts to the whole. The volume of data mentioned above added greatly to the challenge. The final dissertation is not the absolute truth, nor is it complete. The individual stories are one possible interpretation of the data that attempts to illuminate the lived experience of silence from the participants' perspectives. The judgement of it rests with the reader familiar also with this experience. Benner (1994) describes this process by stating "when the canons of textual evidence and consensual validation and dialogue are offered, a citizenry of critical readers and practitioners can discern better and worse interpretative accounts and better or worse ways of articulating common everyday taken-for-granted understandings" (p. 124).

Phenomenology has a major role to play in raising awareness of issues because of its power to make the concerns and practices of people visible and in recommending responses that are reflective of these concerns. When developed wisely, phenomenology can be a powerful tool that allows other voices to be heard, offering an alternative to an ever-increasing economically orientated view of health services.

The reflexive journals formed an invaluable part of writing and thinking, and added to the rigour to the methodology. Writing became a way of knowing, writing was a method, assisting me to discover and analyse and connect the insights on silence and bring them together as a complete whole. I wanted the living meanings of silent moments, silence as suffering and compassion, silence as connection, intuitive silence and gratitude, being silent for others, silent meaning of symbolic language to be grounded in the participants' stories where compassionate caring could be felt at the heart of this essential essence of care. It was important the reader could track this process from the choice of hermeneutic phenomenological methodology and method that supported co-constructed engagement. Literature was explored to support, enlighten and clarify meaning and experience rather than used to expand on knowledge.

Unintended consequence

An unintended consequence of undertaking this research revealed insights from a community perspective. The general community were not part of the research but were noted in my reflexive field journal. The impromptu death café (p. 137) and the bakery story (p. 139) offered insights into how the community may be willing and able to support end-of-life care if we engaged with them more. Dying after all is a societal issue, no one person owns end-of-life care. We all do as members of a caring society and contribute to it in our different ways. Our early history attests to this. The past may well be the path to our future by reclaiming the ancient wisdoms offered by Hippocrates, Asklepios, Larunda and Harpocrates. The hospice movement grew internationally through the work of Dame Cecily Saunders who railed against the dying being deserted. Hearing this message, we inadvertently medicalised the normal and natural process of dying, and need now to integrate knowledge and skills to rebalance societal norms, to work in partnership with health and community. In doing so we may transform the social dimensions of dying, death and bereavement. Considering the Compassionate City ideals when writing policy for our healthcare organisations may assist with reintegration.

Implications for Palliative Care: From understanding to action

This research demonstrates that silence is significant to both the givers and receivers of palliative care and the role of silence is acknowledged across the health professional team. It is not overtly spoken about but is experienced, enabling people to be fully in the moment of time with those in their care. It involves knowing when to be silent, appreciating the many voices of silence, which is extraordinarily difficult to explain and pass on to others. The difficulty in sharing the role of silence in practice, was demonstrated by the participants who acknowledged silence had a role but it was essentially experienced, not heard or fully valued in the fast pace of care. The participants were keen to tell their stories, sharing thoughts easily after the warm-up stories enabled an environment of trust and ease to explore what was important to them. This research establishes that it is possible to share some of the most intimate moments in our practice in the right environment. With the espousal of holistic care, which incorporates the psychological, emotional, cultural and social aspects, we need to explore ways of collecting evidence and making meaning from it. Caring for the dying requires considerable creativity, innovation and highly developed interpersonal skills. Knowing how to care for a human being who faces death captures the richness of palliative care.

Dieklemann (1991) suggests that in telling our stories as nurses, we can learn from each other and come to know practice in new ways. I believe this is true across all health disciplines. Structuring opportunities that regularly enable story telling in the clinical and teaching environments will, I believe, enhance our collective understanding of palliative care experiences. The wisdom captured in these stories allows us to share in the collective consciousness of people giving and receiving palliative care. By the awakening of this consciousness we excite and make possible opportunities to explore the use of silence in our practice. This study indicates the importance of hearing the person/receiver of care and our health professional colleagues as a supportive learning resource as they teach by storying, and become our mentors.

Phenomenological research provides us with insight into the personal experiences of illness and dying. Van Manen (1990) refers to hermeneutic phenomenology as a “critical philosophy for action” (p. 154). He suggests, “hermeneutic phenomenological reflection deepens thought and therefore radicalises thinking and the acting that flows from it” (p.154). This type of research has the potential to encourage a stance of thoughtfulness, which in turn has the potential to motivate us to think critically, challenge our practice, and therefore, improve the quality of care we provide.

Exploring the process that culminates in identifying and honouring the role of silence in palliative care practice and education is important, as we acknowledge being affected by what we do on a daily basis as we interconnect our lives of living and dying. We help to illuminate the importance of this aspect of care and use it wisely to inform practice. To stay comfortably in silence with the despair, unanswerable questions and fear, we need to be comfortable in silence with the self. Personal silence may require time to perfect the art. My personal understanding of this has deepened through this research experience.

From this research I am further convinced that the roles health professionals have in palliative care should revolve strongly around the interpersonal relationships they share with people. Parse's (1987) concept of the nurse as having a 'true presence' reflects my thinking. This relationship involves a way of 'being with' another person which is solely based on being present, open and attentive. Fundamental to 'being with' is the belief that each person knows 'the way' somewhere within self. Each human lives a way, his or her own way, which is both alike and different from the 'ways' of others (Parse, 1990). Given the personal nature of the knowledge on which palliative care is based, there is a case for arguing that the issue in this field of education is not of learning about or in palliative care, but one of learning through palliative care.

Palliative care education and professional development competency frameworks must ensure health professionals have the opportunity to evolve and emerge as more fully human, caring and compassionate beings. Jean Watson's human caring science model (Watson, 2001) is a model to strive towards because it offers new understandings of personhood and of humanity itself, broadening our worldview of caring and healing. It will require a radical transformation of our consciousness, or cosmology and our being in the universe. The learning environment will create a healing space for participants, which will in turn provide ontologically based healing modalities of care for people and families receiving palliative care services.

Consideration

The advantage of this research is the lived experience of journeying with living and dying, people giving and receiving palliative care. Giving voice to what they determined was important therefore a constructed opportunity for learning and discovery. Deep connection with those who were gracious enough to engage with me as the researcher, unfolded the value of Silence from their perspective. It denominated how people who are dying are very willing, along with their families, to engage in research at a very personal and intimate time in their lives. They were not looking necessarily for answers but discovered new meanings in silence that worked to weaved their lives into wholeness. They offered this as a gift for those of us still living, so that we may be able to enrich our own lives and the lives of others through considering the value in their contribution.

Silence and its many voices resonated across the professional health care team. It is a phenomenon not specific to one particular health discipline. It is an insight offered throughout the interprofessional team.

Silence was explored from the perspective of the givers and receivers of palliative care, focusing on the end-of-life. The findings may resonate for some across the life span but may not be generalisable. The participant’s lived experiences of the roles of silence were largely positive but a more and full and robust exploration of silence and the negative components of it would give a more rounded understanding.

Implications for further research

Although I have presented a possible understanding of the experience of the silence between those giving and receiving palliative care, it is a situation-sensitive understanding and further questions arise. This is because the research did not start out to explore this phenomenon, but it emerged as significant and important. Therefore, further questions/thoughts arise to explore this phenomenon further. Silence in this research was largely positive and supportive but, is not always so. As an example: addressing the darker side of silence, when stories are untold, when one is overwhelmed or engulfed by silence. How does maintaining silence impact positively and negatively on wellbeing? How do we help people to find meaning in silence? What are the culture, custom and/or language issues that surround silence in end-of-life care?

I have attempted to create a space for giving a voice to silence in palliative care. I am committed to connecting to the ‘heart’ of the experience of silence and to gathering the stories from participants as the ‘experts’ was something that was in tune with my life-world as a palliative care nurse. The research needs to continue so we are better able to articulate our understanding of this phenomenon and develop our skill and competencies in practice to make a positive difference for those we care for.

From a broader perspective, offered by the unintended engagement with community on this research journey, further research that engages with the community to explore the reality of genuine availability to support end-of-life care would be invaluable. Considering the Compassionate City concept, implementing this strategy within a defined community and evaluating the impact would be beneficial.

The health professional participants almost skipped over the philosophy of palliative care that informs practice, largely due to the pressures of workload and feeling unsupported by the system at large. Further research into the workable reality of this philosophy is worth considering so that we do not set ourselves up to fail before we begin. The WHO philosophy is all encompassing and can certainly act as a guide but should not be seen as a tick box exercise to ensure this all-encompassing care is carried out. Randall and Downie (2006) have offered what they suggest is a more achievable philosophy statement which they suggest is realistic, fair, humane and adoptable across all branches of health and community care:

> Palliative care is the care of patients whose disease is incurable and is expected to cause death within the foreseeable future. The aims of treatment are to minimise pain and other symptoms, and to prolong life, but with a minimum of burdens and risks as assessed by individual patients and professionals working together. The informed consent of competent patients regarding treatment is sought by presenting information honestly but sensitively. Refusal of treatment is respected. (Randall & Downie, 2006, p. 224)

Whilst the WHO philosophy and an alternative consideration offered by Randall and Downie (2006) may be useful to guide practice, further research into how the philosophy can be operationalised in a cost-effective practical sense, needs to be explored. This may reduce anxiety and burnout for health professional teams with increasing demands on services given the burgeoning demographics ahead as noted on page 32-35.

Concluding statement

By undertaking this study, I have been humbled by the opportunity offered to me by the participants – to go to the source of those giving and receiving palliative care to find true meaning in their experience. They highlighted the role and value of silence as part of compassionate respectful caring. They have shone light on a pathway for me to continue to examine ways of determining some of the important principles of quality palliative care. This pathway will utilise phenomenology as a way of revealing truths, which can only be understood by those experiencing them. This has implications for education, clinical practice, further research and nurturing of new practitioners in the field.

In the moments that have been shared by the participants, they have demonstrated through stories of silence, the ability to give hope, love, strength, honesty, intimacy and courage. They have given companionship, support and meaning to those on a dying journey as well as to those journeying with them until that time. They have helped as van Manen (1998) suggests, the patient to recover a liveable relation with his or her psychological being. These activities may appear on the surface as trivial and to many they may not be visible at all. But to the patient and family they bring about profound changes in their lived experience, and to the health professionals they bring professional fulfilment and personal satisfaction. They sustain palliative care health professionals in their intimate involvement with the patients and families amidst suffering, pain, loneliness, loss and grief. By telling their story they describe to us the nature of silence in practice, thus awakening a shift of consciousness that creates new realities and possibilities of teaching, role modelling and mentoring to support best practice in giving and receiving palliative care.

Benner (1994, p. 101) encourages the researcher to ask, “What do I know now or see that I did not expect or understand before I began reading the text?” She suggests that if the researcher’s thinking has not been challenged or altered in some way then it is possible nothing more than the researchers’ preconceptions will emerge. I can assure the reader that this has indeed occurred for me. Completing this research has profoundly impacted on my thinking, critical reflection and the honouring of the learning opportunities given to me by the participants in the study. I feel strongly that I will maintain an openness to the hermeneutic way of learning and review my practice through this lens as well as incorporating it into my educational role to support and journey with my colleagues engaging in palliative care education.

The issue is to stay centred, being still and silent in oneself to hear and be present in the world of another, very much the situation of being present in the moment of dying. In interpretive hermeneutics from Heidegger, I am in my own place of understanding. Understanding can only be through my own way. This understanding has enabled me to think, know and question my practice and has given me the confidence to try.

I shall leave the final word of this thesis to wisdom of Einstein and Infiled (1938) when suggesting a new theory does not invalidate or supersede the old but rather it allows us to regain our old concepts from a higher level. He expands this notion in a famous simile:

> To use a comparison, we could say that creating a new theory is not like destroying an old barn and erecting a skyscraper in its place. It is rather like climbing a mountain, gaining new and wider views, discovering unexpected connections between our starting point and its rich environment. But the point from which we started still exists and can be seen, although it appears smaller and forms a tiny part of our broad view gained by the mastery of the obstacles on our adventurous way up. (p. 159)

Appendices

Appendix A - Courtesy letter to Palliative Care Service Managers

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UC UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

RESPECTFUL COMMUNITIES OF CARE: supporting people living with their dying.

Date

Dear

I am writing this letter as a courtesy gesture as your service has been identified as a key provider of palliative care services in your region and I would like to invite anyone interested within the health care team to be a participant in this research. This study has received ethical approval through the Human Ethics Committee of Canterbury University. This research is undertaken in order to seek a way forward for palliative care in our communities and enables critique of the philosophy of palliative care and current model of service delivery that underpins our current practice.

My research question calls for a human science approach that reveals the perspective of participants, therefore I will use the research method of Hermeneutic Phenomenology. Hermeneutic Phenomenology is interested in people making sense of their world as they experience it. This will require interviewing health professionals using semi structured interviews and may be carried out either in a one on one interview or focus group depending upon their preference. Interviews will be held outside normal working hours.

I would also invite staff to offer the opportunity to participate in the research to consumers of your service, to hear the consumer voice. I will supply information sheets and outline of the study to your service (copies attached for your information). Should a consumer and/or family member wish to participate, staff would forward their contact details to me to follow up, obtain consent, and arrange a suitable time and place to interview them.

It should be noted that the names of participating staff and families will be confidential unless participants themselves wish to divulge their participation in the study. They will be invited to choose a pseudonym should any direct quotes or stories be used in the write up, publications or conference presentations of this research. The location of your service will also be confidential and referred to as rural or urban as an example.

Please don't hesitate to contact me if I can clarify any questions or thoughts you might have. I look forward to working with any of your team who may be interested in this research.

Kind regards

Kate Reid - Researcher
Senior Lecturer in Palliative Care
School of Health Science
University of Canterbury
Private Bag 4800
Christchurch 8140

Appendix B - Cover letter for service provider participants

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UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

COMMUNITIES OF CARE: supporting people living with their dying.

Date

Dear

I am writing to you regarding the research into 'Communities of care: supporting people living with their dying'.

Your service has been identified as a key provider of palliative care services in your region and I would like to invite anyone interested within the health care team to be a participant in this study. I respectfully request that you would pass the information on to your team, seeking their interest in the study. After reading this document outlining information and the process for participating in this study I would be delighted to invite interested people to contact me directly, indicating their interest in joining me in this research.

This research is undertaken in order to seek a way forward for palliative care in our communities, enabling review of service delivery and the philosophy of palliative care that underpins our current practice. Ethical approval has been granted through the Human Ethics Committee of Canterbury University.

The research calls for a human science approach that reveals the perspective of participants, therefore I will use the research methodology of Hermeneutic Phenomenology. Hermeneutic Phenomenology is interested in people making sense of their world as they experience it. This will require interviewing health professionals using semi structured interviews and may be carried out either in a one on one interview or focus group depending upon their preference. Interviews will be held outside normal working hours.

I would also invite staff to offer the opportunity to participate in the research to consumers (patient and or families) of your service, to hear the consumer voice. I will supply information sheets and outline of the study to your service (copies attached for your information). Should a consumer and/or family member wish to participate, staff would invite them to contact me or with their consent, forward their contact details to me to follow up, obtain consent, and arrange a suitable time and place to interview them.

It should be noted that the names of participating staff and families will be confidential unless participants themselves wish to divulge their participation in the study. They will be invited to choose a pseudonym should any direct quotes or stories be used in the write up, publications or conference presentations of this research. The location of your service will also be confidential and referred to as rural or urban as an example.

Please don't hesitate to contact me if I can clarify any questions or thoughts you might have. I look forward to working with any of your team who may be interested in this research.

Kind regards

Kate Reid (Researcher)
Senior Lecturer in Palliative Care
School of Health Science
University of Canterbury
Private Bag 4800
Christchurch 8140

Email: kate.reid@canterbury.ac.nz

Appendix C - Information for service provider - participants sheet

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COMMUNITIES OF CARE: supporting people living with their dying.

The principle investigator in this study is Kate Reid – MA, RN. I have been a palliative care nurse for the past 30 years in a variety of roles from bedside practice, leadership, management, education and governance positions and am now sharing that experience as a Senior Lecturer in the School of Health Sciences at the University of Canterbury.

This study has approval from the Human Ethics Committee of the University of Canterbury.

Kate can be contacted via; telephone: (03) 3667001 ext. 3680
email: kate.reid@canterbury.ac.nz

Thank you for showing interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, I thank you. If you decide not to take part there will be no disadvantage of any kind and I thank you for considering my request.

THE STUDY
This study is about understanding communities of care: supporting people living with their dying.

This research is undertaken in order to seek a way forward for palliative care in our community and enables reflection on current service delivery and review of the philosophy of palliative care that underpins current practice. For your information – the World Health Organisation and NZ working party definitions of palliative care are attached (appendix A). Taking the time to refresh your understanding of these definitions may help in reflecting upon the current system of care prior to the interview or focus group session.

The study aims to explore and to conceptualise the experience of the health professionals involved in palliative care delivery and to explore and describe the experience, thoughts and ideas of the person / family who are consumers of the palliative care service by:
1. Describing, identifying and portraying the personal experiences of those who give and receive care at the end of life.
2. Documenting the experiences and perceptions of delivering palliative care that is in accordance with the World Health Organisation and Ministry of Health philosophy of care.
3. Identifying any unmet needs or opportunities for improvements in the provision of palliative care in the future.

I will be conducting a semi-structured interviews or focus groups (depending on your preference) as a catalyst for you to share your thought, ideas and experiences. Your contributions will help to ensure the future of palliative care is meets the needs of our community in end of life care.

THE RESEARCH PROCESS
Once you have contacted me indicating your willingness to take part, I will send you a biographical data sheet and consent form. The biographical data is completely voluntary information and you can choose to share what you wish. The consent form will need to be signed by both of us before the interview or focus group takes place.
After you give verbal and written consent to participate in the study we will organise the interview or focus group. This will be audio taped and transcribed by a transcriber who will have signed a

confidentiality agreement. You will be given a copy of this interview for your own utilisation and also so you can validate the accuracy of the transcription.

YOUR RIGHTS
Your rights as a participant include the right to refuse to continue at any stage of the research process. You can withdraw your stories at any time up until the point of analysis which you will be informed about, and all data will be given to you or destroyed.

You have the right to confidentiality and privacy throughout the research process. This means that only you and me (and if it is a focus group, then those present in that group) will know you are a participant in the study. This does not stop you from telling others though if you wish but you must only discuss your own experiences and respect the privacy and confidentiality of colleague's experiences that they share in the focus group.

Your ideas, thoughts, stories from the interview will be kept securely locked in a filing cabinet in my locked office at the University. Electronic copies of information will be held on a password protected computer in my University office. The safety and security of the data is my responsibility. Data will be kept for 10 years and then destroyed, in accordance with the University of Canterbury's Record Management Policy.

CONSENT
Your informed consent means that you have read this information sheet and are happy with all the details in it.

As part of writing up of this research I will probably use direct quotes or stories in order to illustrate significant contributions to practice or service delivery. In this instance what you said will be written for all to see. Please indicate on the consent form which your preference is. If you would like your real name (first name only) or a pseudonym of your choice to be alongside the example it is important that you sign the consent to this.

You will be able to ask me about any step or part of the research process at any time. If you have any concerns regarding this research during any part of the process you are encouraged to contact the University of Canterbury Ethics Committee of or my supervisory team Prof. Ann Richardson, Prof. Andrew Hornblow and Prof. Sandy Macleod at the School of Health Sciences, University of Canterbury. (Contact details below).

You have the right to determine the time, place and general conditions of your interview and you may bring a support person if you like. Should you select to part of a focus group, the time will be determined / coordinated by those attending. If you identify as a Maori, I will endeavour to follow your wishes regarding consultation with appropriate whanau, hapu or iwi, and work alongside the cultural advisor in your service.

Sometimes during interviews where people are telling important or sensitive information they can become emotional. If you feel like you need a break during the interview or you would like the tape stopped – just ask and it will be turned off. If you feel that the interview raises issues for you that need to be addressed further, I will arrange for a trained counsellor or cultural support person to be available at no cost to you.

Please do not hesitate to contact me if I can be of further assistance. I look forward to hearing from you.

Kind Regards

Kate Reid - Researcher
Senior Lecturer in Palliative Care
School of Health Science
University of Canterbury
Private Bag 4800
Christchurch 8140

Human Ethics Committee
University of Canterbury
Private Bag 4800
Christchurch 8140
human-ethics@canterbury.ac.nz

Prof Ann Richardson ann.richardson@canterbury.ac.nz
Prof Sandy Macleod sandy.macleod@canterbury.ac.nz
Prof Andrew Hornblow a.d.hornblow@xtra.co.nz
School of Health Science
University of Canterbury
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World Health Organisation Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

http://www.who.int/cancer/palliative/definition/en/

New Zealand Palliative Care: A Working Definition.

From: Palliative Care Subcommittee, NZ Cancer Treatment Working Party
26 February 2007

In applying the WHO definitions, New Zealand also needs to take into account the following:

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection. In addition, we must acknowledge and include He Korowai Oranga (the Māori Health Strategy (2002)). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Whā (four-sided house) towards health/wellbeing is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau(family health).

2. Palliative care continues to evolve. Thus, definitions need to be flexible enough to adapt to changes in society, disease and illness, and individual and society’s expectations. Palliative care recognises and respects the rights of patients as detailed in the Code of health and Disability Services Consumers’ Rights.

3. Generalist Palliative Care will be available throughout the course of a life limiting illness, with specialist palliative care provided on the basis of assessed need, rather than simply diagnosis or prognosis. Palliative care will also be available wherever the patient is – be that home, hospital, residential care, or hospice. Palliative care is centred on the patient and family / whānau. The level of palliative care support required for any individual, family or whānau is dynamic and varies during the course of illness (and into bereavement).

4. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whanau in contemporary New Zealand society.

5. Palliative care is best delivered through an integrated approach to care that recognises the roles and responsibilities of both palliative care generalists and specialists, in meeting palliative care need. This integrated model or framework of care delivery is essential for effective palliative care provision.

6. The patient’s primary care team will continue to provide continuity of care through illness. Depending on need, the involvement of specialist palliative care may be episodic or continuous.

7. In the case of children and young people, palliative care will also be available on the basis of assessed need. Specialist palliative care will be provided in collaboration with formally trained or experienced paediatric healthcare professionals either community (e.g. GP, district nurse) or hospital based. In New Zealand, home is the preferred and usual location for palliative care for children and young people. It is recognised, however, that some children and young people spend long periods of time in tertiary hospitals far from the primary care team.

Therefore, the New Zealand definition of Palliative Care is:

Care for people of all ages with a life-limiting illness which aims to:

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.

2. Support the individual's family, whanau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all heath care professionals, supported where necessary,
by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities.

www.health.govt.nz/system/files/.../nz-palliative-care-definition-oct07.pdf

Appendix D - Health Professional Consent to participate in the study

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UNIVERSITY OF CANTERBURY
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CHRISTCHURCH NEW ZEALAND

COMMUNITIES OF CARE: supporting people living with their dying.

I have read the information for participants' sheet regarding the study designed to explore the current service provision and future of palliative care in our community. I have had the opportunity to discuss this study with the researcher and I am satisfied with the answers that I have been given.

I understand that taking part in this study is voluntary and that I may withdraw from the study at any time up until the analysis of the data takes place.

I understand that if I wish to withdraw from the study my data will be destroyed or given to me.

I understand that my data will be kept locked in a secure cabinet during the study.

I understand that my participation in this study is confidential and that any information I provide will be kept confidential to the researcher, her supervisors and the professional transcriber. My identity will remain protected throughout the study process and through any potential publications and presentations. I am aware that excerpts, stories, or direct quotations from my interview transcripts may be used to illustrate points during the writing up of this project and subsequent publications or presentations.

I have had time to consider whether to participate.

I am aware that this study has ethics approval from the Human Ethics committee of the University of Canterbury.

I know who to contact if I have any questions regarding the ethics of this study.

I consent to my interview being audio taped and transcribed by a professional transcriber.

I wish to receive a copy of my transcript. YES/NO

If you wish to receive a copy of the transcript please provide your address.

I wish to be informed when the results are available to be read YES/NO

I wish to use my first name on any potential written reports YES/NO

I would like a pseudonym used on any potential written reports YES/NO
Pseudonym____

I know I have access to counselling support should I require this service.
YES/NO
I ____ hereby consent to take part in this study.

Signature _____________________________ Date______________
Researcher____________________________ Date ______________

Appendix E - Human Ethics Committee Approval

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2013/122

30 September 2013

Kate Reid
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear Kate

The Human Ethics Committee advises that your research proposal “Communities of care: supporting people living with their dying” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 19 September 2013.

Best wishes for your project.

Yours sincerely

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

University of Canterbury Private Bag 4800, Christchurch 8140, New Zealand. www.canterbury.ac.nz

Appendix F - Maori Ethics Committee Approval

From: John Pirker <john.pirker@canterbury.ac.nz>
Sent: Thursday, 29 August 2013 2:28 PM
To: Kate Reid <kate.reid@canterbury.ac.nz>
Subject: Maori Consultation - Communities of care: supporting people living with their dying

Tene koe Kate,

Re: Communities of care: supporting people living with their dying.

I write on behalf of the Maori Research Advisory Group (MRAG). Thank you for your Maori consultation form that you submitted as part of your research proposal. This letter serves to acknowledge that your proposal has passed through the Maori Research Advisory Group (MRAG) at the University of Canterbury. I am very pleased to advise that the Maori Research Advisory Group is very supportive of your research. It was felt that your research will significantly add to the current literature about palliative care and the Maori experience. MRAG is satisfied that you have considered any possible important cultural aspects of your research and supports this application.

It would be appreciated if a summary of your findings could be presented to the MRAG upon its completion. We wish you all the best in your research and please feel free to contact me if you have any further questions. If you require a hard copy of this letter, please let me know and I'll arrange to have one forwarded to you.

Naku noa (Yours sincerely)

John Pirker
School of Biological Sciences/College of Science
Research Consultant-Maori (Acting)
University of Canterbury
Private Bag 4800
Christchurch 8020
New Zealand

http://www.biol.canterbury.ac.nz/
Ph: +64 +3 364 3050
Fax: +64 3 364 2590
Skype: john.pirker

Appendix G - Semi Structured Interview Guide Sheet

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Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

COMMUNITIES OF CARE: supporting people living with their dying.

Main Questions for consumer participants:

Can you tell me about your experience of the hospice (or palliative care) service and its philosophy of care?

What impact has this experience had on your life at this present time?

Prompt questions if required:

Do you have any comments, thoughts or suggestions for the future of hospice / palliative care that would be helpful for your community?

What do you feel or think is important for health professionals to know about caring for people either living with a life challenging illness or caring for people who are dying?

Main Questions for service provider participants:

Can you tell me about your experience of the effectiveness of the philosophy of palliative care and its clinical application in your community?

Prompt questions if required:

Do you have any comments, thoughts or suggestions for the future of hospice / palliative care that would be helpful for your community?

Appendix H - Letter for consumer participants

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UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

COMMUNITIES OF CARE: supporting people living with their dying.

Date

Dear

Your name and contact details have been forwarded to me by the ----------- palliative care service, as someone who may be interested in participating in the above research study.

I have enclosed an information sheet and consent form for you to read and consider. In about a week's time, I will contact you by phone to offer you an opportunity to discuss and clarify any questions you may have about the study. Following this contact, you may wish to deliberate for a further 2-3 days before you make your final decision to participate or not.

Thank you very much for taking the time to read this information and consider being part of this research. I look forward to talking with you further.

Kind regards

Kate Reid (Researcher)
Senior Lecturer in Palliative Care
School of Health Science
University of Canterbury
Private Bag 4800
Christchurch 8140

Email: kate.reid@canterbury.ac.nz

Appendix I - Information for consumer participants sheet

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COMMUNITIES OF CARE: supporting people living with their dying.

The principle investigator in this study is Kate Reid – MA, RN. I have been a palliative care nurse for the past 30 years in a variety of roles from bedside practice, leadership, management, education and governance positions and am now sharing that experience as a Senior Lecturer in the School of Health Sciences at the University of Canterbury.

This study has approval from the Human Ethics Committee of the University of Canterbury.

Kate can be contacted via; telephone: (03) 3667001 ext. 3680
email: kate.reid@canterbury.ac.nz

Thank you for showing interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, I thank you. If you decide not to take part there will be no disadvantage of any kind and I thank you for considering my request.

THE STUDY
This study is about understanding communities of care: supporting people living with their dying.

This research is undertaken in order to seek a way forward for palliative care in our community and enables reflection on current service delivery and review of the philosophy of palliative care that underpins current practice. For your information –the World Health Organisation and NZ working party definitions of palliative care are attached (appendix A). Taking the time to read these ideas on palliative care would be greatly appreciated as you may be able to offer value comment given your experience of being part of this service, in helping to shape a helpful way forward for the community. This study aims explore and describe experience, thoughts and ideas of the person / family who are consumers of the palliative care service by:

1. Describing, identifying and portraying the personal experiences of those who receive palliative care according to the World Health Organisation and Ministry of Health philosophy of care.
2. Documenting any unmet needs or opportunities for the provision of palliative care in the future.

I will be conducting a semi-structured interviews as a catalyst for you to share your thought, ideas and experiences. Your contribution will help to ensure the future of palliative care meets the needs of our community in end of life care.

THE RESEARCH PROCESS
Once you have contacted me indicating your willingness to take part, or given permission for your health professional to contact me indicating your interest in taking part, I will send you a biographical data sheet and consent form. The biographical data is completely voluntary information and you can choose to share what you wish. The consent form will need to be signed by both of us before the interview takes place.

After you give verbal and written consent to participate in the study we will organise the interview or focus group. This will be audio taped and transcribed by a transcriber who will have signed a confidentiality agreement. You will be given a copy of this interview for your own utilisation and also so you can validate the accuracy of the transcription.

YOUR RIGHTS

Your rights as a participant include the right to refuse to continue at any stage of the research process. You can withdraw your stories at any time up until the point of analysis. You will be advised when this occurs. If you withdraw all data will be destroyed.

Your decision to participate (or not) or to withdraw, will not impact on the care you and your family receive. Your health care needs will still be met by your service provider regardless of your decision over this research.

You have the right to confidentiality and privacy throughout the research process. This means that only you and I will know you are a participant in the study. This does not stop you from telling others though if you wish. Your health care provider will not be told any information from the interview; it is strictly confidential between you and me as the researcher.

Your ideas, thoughts, stories from the interview will be kept securely locked in a filing cabinet in my locked office at the University. Electronic copies of information will be held on a password protected computer in my University office. The safety and security of the data is my responsibility. Data will be kept for 10 years and then destroyed in accordance with the University of Canterbury's Record Management Policy.

CONSENT

Your informed consent means that you have read this information sheet and are happy with all the details in it.

As part of writing up of this research I will probably use direct quotes or stories in order to illustrate significant contributions to practice or service delivery. In this instance what you said will be written for all to see. Your real name will not be used but rather a pseudonym of your choice will be used alongside the example and it is important that you sign the consent for this.

You will be able to ask me about any step or part of the research process at any time. If you have any concerns regarding this research during any part of the process you are encouraged to contact the University of Canterbury Ethics Committee of or my supervisory team Prof. Ann Richardson, Prof. Andrew Hornblow and Prof. Sandy Macleod at the School of Health Sciences, University of Canterbury. (Contact details below).

You have the right to determine the time, place and general conditions of your interview and you may bring a support person if you would like. If you identify as a Maori, I will endeavour to follow your wishes regarding consultation with appropriate whanau, hapu or iwi, and work alongside the cultural advisor in your service.

Sometimes during interviews where people are telling important or sensitive information they can become emotional. If you feel like you need a break during the interview or you would like the tape stopped – just ask and it will be turned off. If you feel that the interview raises issues for you that need to be addressed further, I will arrange for a trained counsellor or cultural support person to be available at no cost to you.

Please do not hesitate to contact me if I can be of further assistance. I look forward to hearing from you.

Kind Regards

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World Health Organisation Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

http://www.who.int/cancer/palliative/definition/en/

New Zealand Palliative Care: A Working Definition.

From: Palliative Care Subcommittee, NZ Cancer Treatment Working Party
26 February 2007

In applying the WHO definitions, New Zealand also needs to take into account the following :

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection. In addition, we must acknowledge and include He Korowai Oranga (the Māori Health Strategy (2002)). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Whā (four-sided house) towards health/wellbeing is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau(family health).

2. Palliative care continues to evolve. Thus, definitions need to be flexible enough to adapt to changes in society, disease and illness, and individual and society's expectations. Palliative care recognises and respects the rights of patients as detailed in the Code of health and Disability Services Consumers' Rights.

3. Generalist Palliative Care will be available throughout the course of a life limiting illness, with specialist palliative care provided on the basis of assessed need, rather than simply diagnosis or prognosis. Palliative care will also be available wherever the patient is – be that home, hospital, residential care, or hospice. Palliative care is centred on the patient and family / whānau. The level of palliative care support required for any individual, family or whānau is dynamic and varies during the course of illness (and into bereavement).

4. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whanau in contemporary New Zealand society.

5. Palliative care is best delivered through an integrated approach to care that recognises the roles and responsibilities of both palliative care generalists and specialists, in meeting palliative care need. This integrated model or framework of care delivery is essential for effective palliative care provision.

6. The patient's primary care team will continue to provide continuity of care through illness. Depending on need, the involvement of specialist palliative care may be episodic or continuous.

7. In the case of children and young people, palliative care will also be available on the basis of assessed need. Specialist palliative care will be provided in collaboration with formally trained or experienced

paediatric healthcare professionals either community (e.g. GP, district nurse) or hospital based. In New Zealand, home is the preferred and usual location for palliative care for children and young people. It is recognised, however, that some children and young people spend long periods of time in tertiary hospitals far from the primary care team.

Therefore, the New Zealand definition of Palliative Care is:

Care for people of all ages with a life-limiting illness which aims to:

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.

2. Support the individual's family, whanau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all heath care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities.

www.health.govt.nz/system/files/.../nz-palliative-care-definition-oct07.pdf

Appendix J - Consumer Consent to participate in the study

School of Health Sciences
Tel: +64 3 366 7001 ext. 8691
www.health.canterbury.ac.nz
healthsciences@canterbury.ac.nz

COMMUNITIES OF CARE: supporting people living with their dying.

I have read the information for participants' sheet regarding the study designed to explore the current service provision and future of palliative care in our community. I have had the opportunity to discuss this study with the researcher and I am satisfied with the answers that I have been given.

I understand that taking part in this study is voluntary and that I may withdraw from the study at any time up until the analysis of the data takes place.

I understand that if I wish to withdraw from the study my data will be destroyed or given to me.

I understand that my data will be kept locked in a secure cabinet during the study.

I understand that my participation in this study is confidential and that any information I provide will be kept confidential to the researcher, her supervisors and the professional transcriber. My identity will remain protected throughout the study process and through any potential publications and presentations. I am aware that excerpts, stories, or direct quotations from my interview transcripts may be used to illustrate points during the writing up of this project and subsequent publications or presentations.

I have had time to consider whether to participate.

I am aware that this study has ethics approval from the Human Ethics Committee of the University of Canterbury.

I know who to contact if I have any questions regarding the ethics of this study.

I consent to my interview being audio taped and transcribed by a professional transcriber.

I wish to receive a copy of my transcript. YES/NO

If you wish to receive a copy of the transcript please provide your address.

I wish to be informed when a summary of the results is available to be read YES/NO

I would like a pseudonym used on any potential written reports YES/NO
Pseudonym____

I know I have access to counselling support should I require this service.
YES/NO

I ____ hereby consent to take part in this study.

Signature ______________________________ Date_______________
Researcher______________________________ Date _______________

Appendix K - Transcriber confidentiality agreement

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UC UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

COMMUNITIES OF CARE: supporting people living with their dying.

To ensure confidentiality for the persons being interviewed

I, -- as transcriber of this research for Kate Reid, understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have a responsibility to honour this confidentially agreement.

I will not divulge any information contained in the transcripts I produce, with anyone except the Researcher of this project and/or her Supervisors.

I agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. tapes, transcripts) with anyone other than the Researcher or her Supervisors.
2. Keep all research information in any form or format (e.g. tapes, transcripts) secure while it is in my possession.
3. Return all research information in any form or format (e.g. tapes, transcripts) to the Researcher when I have completed the transcription tasks.
4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g. information stored on my computer hard drive).

Signature

Date

Thank you for signing this agreement

Signature

Date

Kate Reid
Researcher

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